The Maine Comprehensive Cancer Control Plan 2001- 2005

TABLE OF CONTENTS

Acknowledgements and Dedication . . . . . **v**

Introduction **1**

The Burden of Cancer in Maine 4

Highlights of Cancer Control in Maine 10

Comprehensive Cancer Planning In Maine 13

Primary Prevention **15**

Tobacco Use 18

Nutrition and Physical Activity 24

Exposure to Ultraviolet Radiation 26

Sexual Health 28

Exposure to Environmental and Occupational Carcinogens 30

Early Detection 35

Breast Cancer 37

Colorectal Cancer 40

Cervical Cancer 43

Prostate Cancer 46

Skin Cancer 48

Genetics 50

Treatment **53**

Rehabilitation and Survivorship **59**

Palliative and Hospice Care **63**

Data and Cancer Surveillance **69**

Implementation **73**

Evaluation **77**

Appendices **81**

Appendix A Terms and Acronyms 83

Appendix B Mandated Health Insurance Benefits Related to Cancer 87

Appendix C Summary of Maine Tobacco Laws 88

Appendix D National Cancer Prevention and Screening Guidelines Sources 89

References **90**

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Like most comprehensive planning endeavors, the development of the Consortium and this plan was not done single-handedly; many organizations and individuals contributed countless hours in order to create this initiative.

A special thanks is extended to the Consortium co-chairs Don Magioncalda, MD, MaineGeneral Medical Center and Karen O'Rourke, MPH, Maine Center for Public Health, for their dedication to and insights into cancer prevention, control, and care in Maine.

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We extend our thanks to the chairs and members of the Consortium Work Groups. Their hard work provides the foundation for this Plan. The names of each of these Work Group members can be found at the beginning of each Work Group section.

In addition, support and technical assistance was given to the Consortium by the Centers for Disease Control and Prevention and the Battelle Centers for Public Health Research and Evaluation. We also thank Tom Kean, Strategic Health Concepts, for his work in guiding the Consortium through much of its planning process.

We gratefully acknowledge the work of other states including Michigan, North Carolina, Colorado, Texas, Massachusetts, and the Northwest Portland Area Indian Health Board, who generously shared their experiences in developing a comprehensive cancer control program. Also, we acknowledge the other model planning states, Arkansas, Illinois, Kentucky, Utah, and Kansas; thank you for being with us each step of the way.

Finally, we would like to thank the Consortium members for their energy, interest, and dedication to improving cancer prevention and control efforts in Maine.

The Maine Comprehensive Cancer Control Plan is dedicated to people in Maine who have been touched by cancer. This Plan will hopefully reduce your numbers.

INTRODUCTION

INTRODUCTION

Cancer is not just one disease. It is a group of diseases that include a process of abnormal and uncontrolled growth and spread of cells. Cancers are caused by internal (e.g., genetic and hormonal) and external (e.g., viral, social, and environmental) factors.

The 1990s saw the overall cancer death rate in the United States decline for the first time since such information has been tracked. Unfortunately, Maine did not experience the same decrease. Not all the news is bad, however. Significant progress has been made toward reducing the impact of several major cancers and initiating several statewide initiatives to address others. Cancer prevention, early detection, and care have undergone significant change since 1990 and have major implications for the future.

Each year approximately 6,800 Maine residents are diagnosed with cancer and 3,100 die from the disease.[1] Cancer is the second leading cause of death in Maine. Only heart diseases cause more deaths in Maine. Cancer results in the loss of more years of healthy life than heart disease, however, because cancer deaths occur at younger ages.

Cancer is also a costly disease. In 1997, 6,636 hospitalizations occurred in Maine as a result of cancer. Direct and indirect costs of cancer in Maine totaled nearly $440 million in 1997.[2] The economic, psychological, and social burden of cancer on individuals, families, and communities is beyond measure. This burden can be dramatically reduced if proven advances in prevention, early detection, and care are made available to all Mainers. Recognizing this need, the Maine Bureau of Health (MBOH) invited representatives from public and private organizations involved in all areas of cancer prevention, control, and care to become part of the Maine Consortium for Comprehensive Cancer Control (hereafter referred to as the Consortium).

The Consortium began a systematic planning process with the establishment of Work Groups that gathered and analyzed data and information to identify cancer burden, populations at risk, risk factors responsible, available prevention, control, and treatment programs and services, and gaps in data. After extensive review of cancer-related data and possible strategies to reduce cancer morbidity and mortality, the Work Groups developed goals and specific, measurable objectives for reducing the burden of cancer in Maine. These goals and objectives are the foundation for this Comprehensive Cancer Control Plan (hereafter referred to as the Plan).

The Plan provides detailed, specific actions to be taken over the next 5 years for high-priority activities in primary prevention, early detection, treatment, rehabilitation, survivorship, palliation, and hospice care. These priority activities are based on decisions made by the Consortium and on science and current best practices in cancer prevention, control, treatment, and care. As new data become available, these will be reviewed and used for future planning efforts.

The purpose of the Plan is to serve as a blueprint for what can and should be done to provide statewide coordination of cancer control and care efforts in Maine. It identifies specific roles for coordinated action by government, the private sector, the non-profit sector, and Maine's communities and citizens.

Cancer is a complex disease requiring a variety of interventions. Many cases of cancer can be prevented. Other cancers can be detected early and diminished, controlled, or cured. It is our duty to provide Mainers with the information and supportive communities and workplaces they need to reduce their risk

of developing cancer. We need to make Mainers aware that cancer services are available and accessible. We need to provide Mainers with information about cancers that can be controlled or cured. Access to high-quality screening and state-of-the-art treatment must be available. Even for cancers for which there is currently no cure, there are life-prolonging, life-enhancing, and pain-control measures to which Mainers deserve access. This Plan provides specific objectives and strategies that, once achieved, will reduce the burden of cancer in Maine.

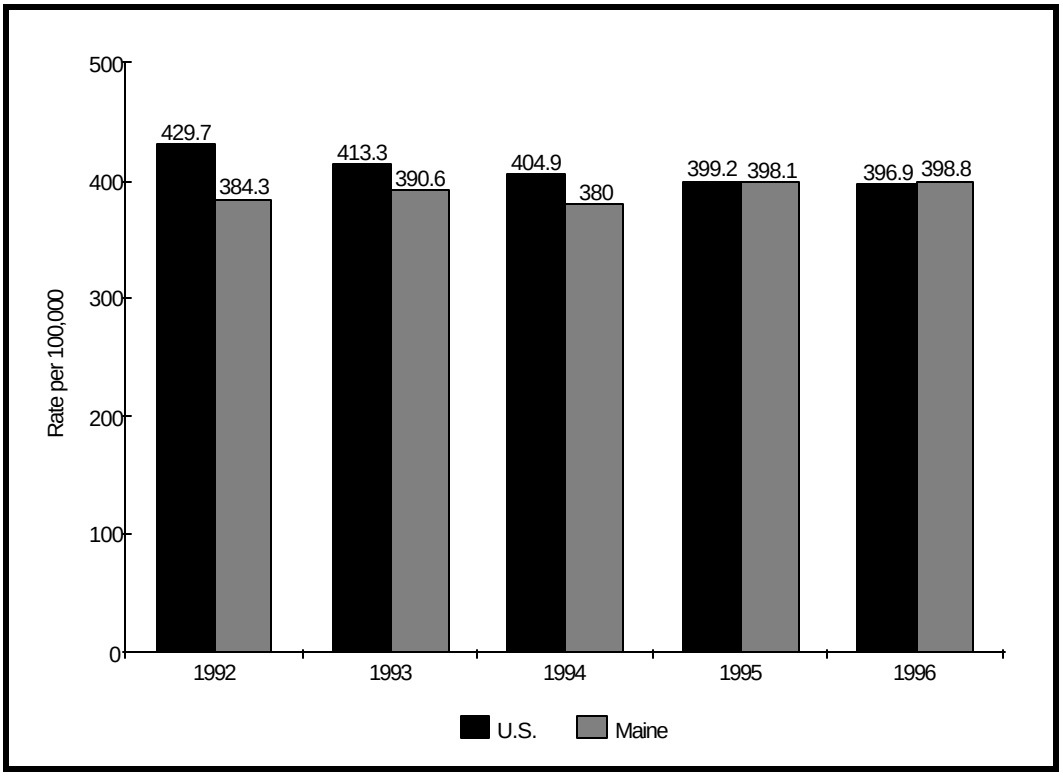
THE BURDEN OF CANCER IN MAINE

INCIDENCE, MORTALITY, COSTS

The burden of cancer in Maine is heavy in terms of cancer incidence, mortality, and costs.

Incidence. Cancer incidence is the number of newly diagnosed cases of cancer occurring in a population in a given period of time. Maine's cancer incidence rate in 1996 of 398.8 per 100,000 population was slightly higher than that of the United States (396.9 per 100,000 white population, 1996, Figure 1). While the United States incidence rates appear to be declining, Maine incidence rates do not.

Figure 1 Total Cancer Incidence By Year, Maine vs. United States, 1992-1996

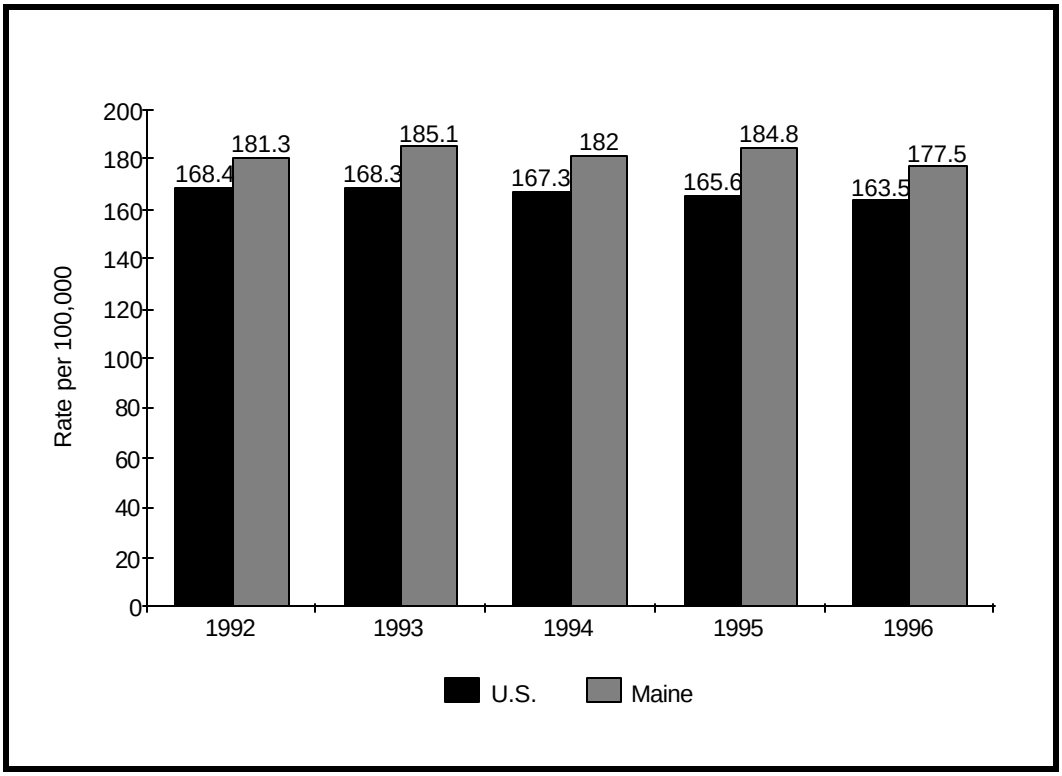


Note: Sources for all United States cancer incidence data are from the Surveillance, Epidemiology and End Results Program, Division of Cancer Control and Population Sciences, National Cancer Institute. U.S. rates are for the Caucasian population only, since this provides a better comparison with Maine's population, which is approximately 98 percent Caucasian. Sources for all Maine cancer incidence data are the Maine Cancer Registry, Bureau of Health, Maine Department of Human Services. All sites are invasive, rates are per 100,000, directly age-adjusted to the U.S. 1970 standard population.

Each year approximately 6,800 Maine residents are diagnosed with cancer, which equals 18.5 per day. The four leading cancer diagnoses in Maine are lung, breast, prostate, and colorectal cancers. In 2000, approximately 1,000 Mainers will be diagnosed with lung and bronchus cancer, 900 women will be diagnosed with breast cancer, 900 men will be diagnosed with prostate cancer, and 700 people will be diagnosed with colorectal cancer.[3] The incidence rates for the four leading cancer diagnoses in Maine for 1995 and 1996 can be seen in Figures 3-6.

Mortality. Cancer mortality is the number of deaths due to cancer or a particular type of cancer. Maine's cancer mortality rate in 1996 of 178.2 per 100,000 population was higher than that of the United States (163.5 per 100,000, Figure 2). Maine's cancer mortality rates for 1992-1995 were also higher than the U.S. rates for this time period.

Figure 2 Total Cancer Mortality By Year, Maine vs. United States, 1992-1996



Note: Sources for all United States cancer mortality data are from the National Center for Health Statistics. U.S. rates are for the Caucasian population only, since this provides a better comparison with Maine's population, which is approximately 98 percent Caucasian. Sources for all Maine cancer mortality data are the Maine Cancer Registry, Bureau of Health, Maine Department of Human Services. All sites are invasive, rates are per 100,000, directly age-adjusted to the U.S. 1970 standard population.

Cancer is the second leading cause of death in Maine, exceeded only by heart disease.[4] Approximately 3,100 Mainers die from cancer each year, 8.5 per day. The leading causes of cancer deaths in Maine are lung, colorectal, breast, and prostate cancer. In 2000, approximately 900 Mainers will die from lung cancer, 300 from colorectal cancer, and 200 each from breast cancer, prostate cancer, cancer of the pancreas, and Non-Hodgkin's lymphoma.[5] The mortality rates for the four leading cancer diagnoses in Maine for 1995 and 1996 can be seen in Figures 3-6.

Figure 3 Lung Cancer Incidence and Mortality By Year, Maine vs. United States, 1995-1996

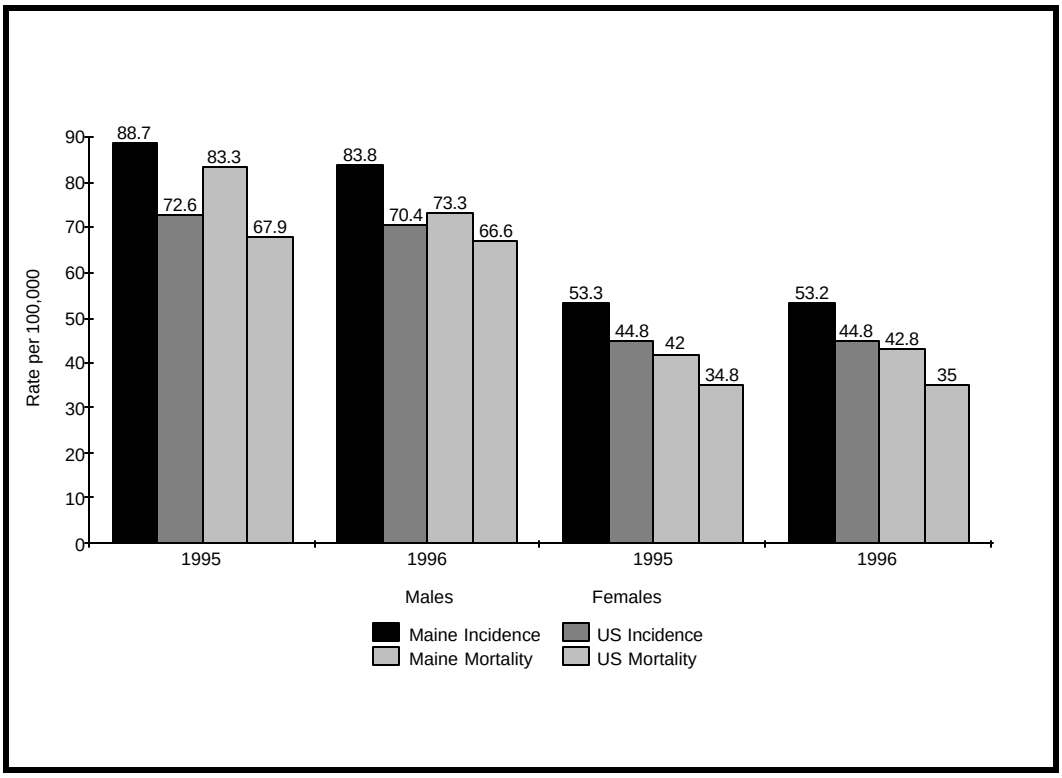


Figure 4 Colorectal Cancer Incidence and Mortality By Year, Maine vs. United States, 1995-1996

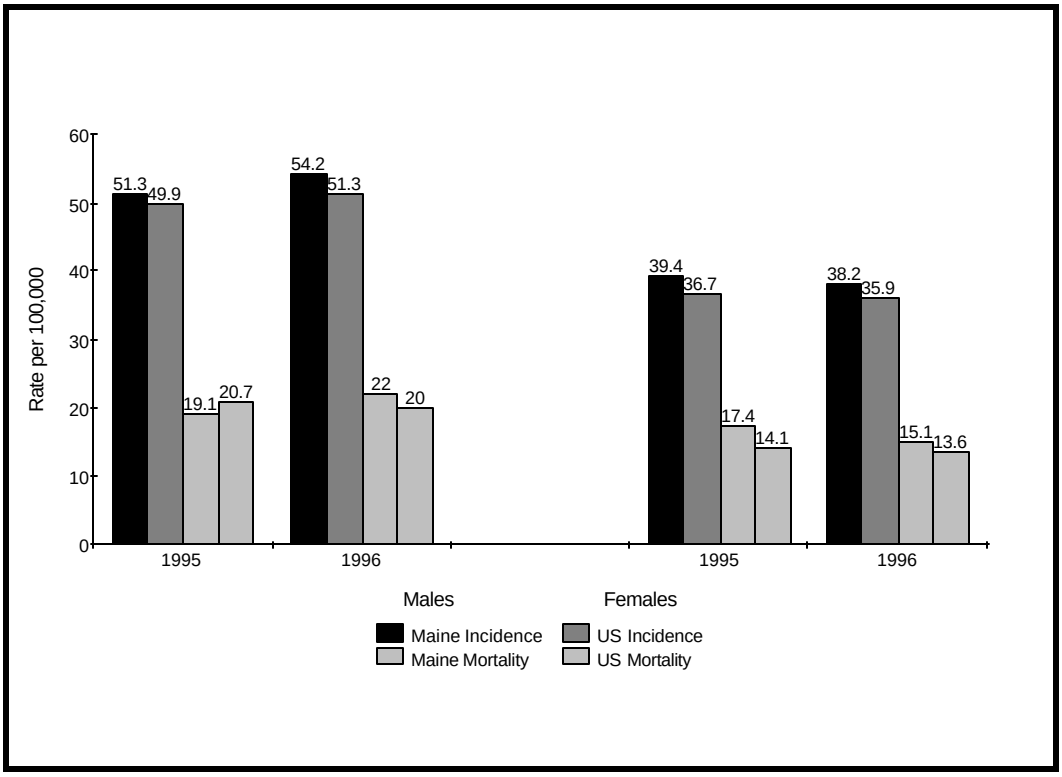


Figure 5 Female Breast Cancer Incidence and Mortality By Year, Maine vs. United States, 1995-1996

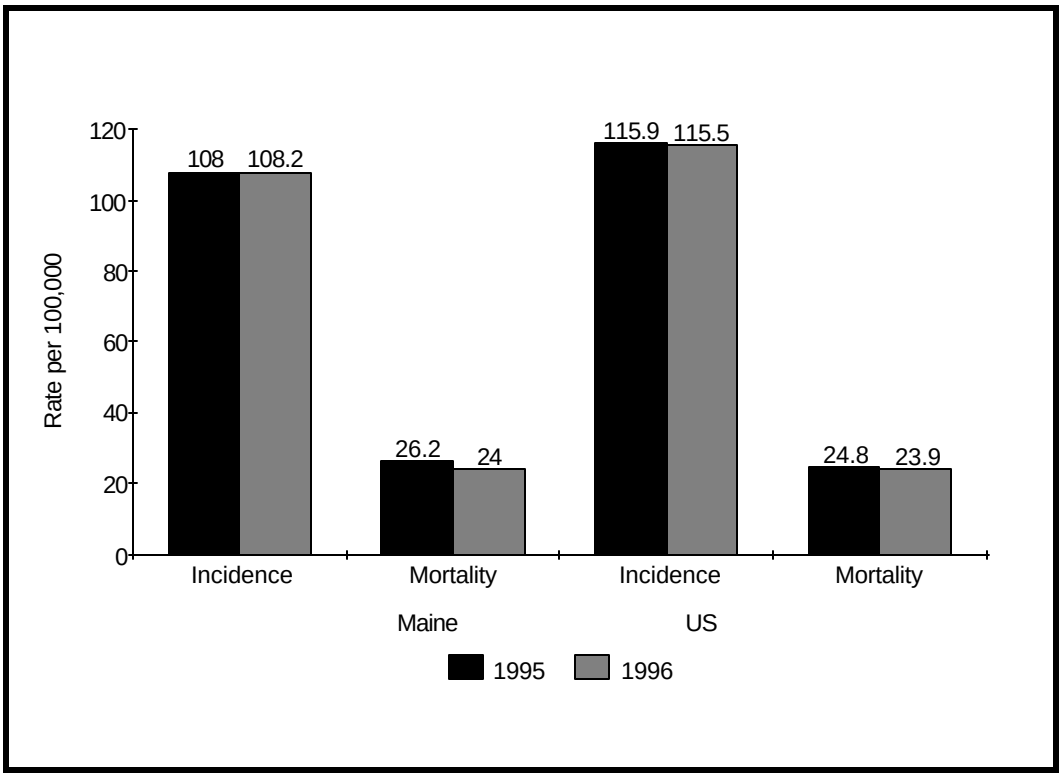
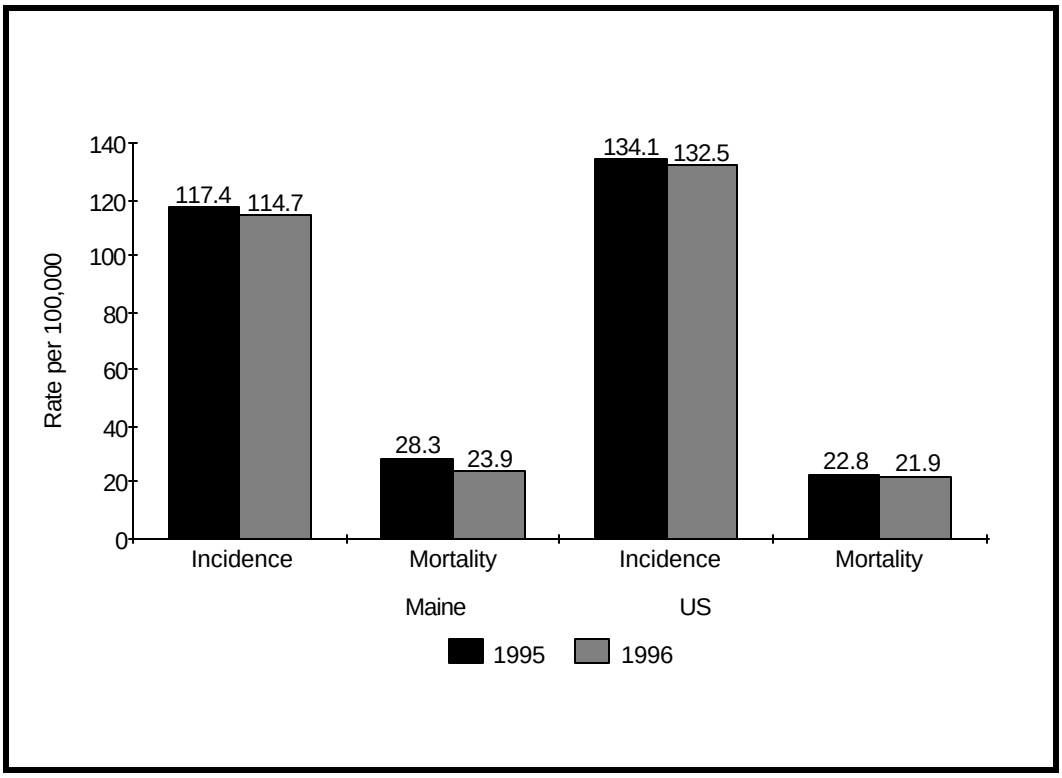


Figure 6 Prostate Cancer Incidence and Mortality By Year, Maine vs. United States, 1995-1996



Lung cancer mortality for males is significantly higher in Maine than in the United States. Mortality in Maine is similar to that in the United States for breast, prostate, and colorectal cancers. It is interesting to note that, while mortality rates for female breast cancer and for prostate cancer are similar to the United States, Maine's incidence rates appear lower. Further investigation is needed to determine whether this is an issue related to stage at diagnosis (i.e., an issue of early detection), to treatment (e.g., choice of type of treatment, delay in treatment), or to underreporting of cancer cases.

Cost. The National Institutes of Health estimates overall annual costs for cancer at $107 billion for the United States; $37 billion for direct medical costs (total of all health expenditures), $11 billion for indirect morbidity costs (cost of lost productivity due to illness), and $59 billion for indirect mortality costs (cost of lost productivity due to premature death). Treatment of breast, lung, and prostate cancers account for over half of the direct medical costs.[6]

In 2000, the cost of cancer for Maine is estimated to reach $600 million for all cancer-related costs in 2000: $200 million for direct medical costs, $61 million for indirect morbidity – lost productivity due to illness, and $330 million for mortality – lost productivity due to premature death.[7]

Facts about Maine's Population That Impact Cancer Risk

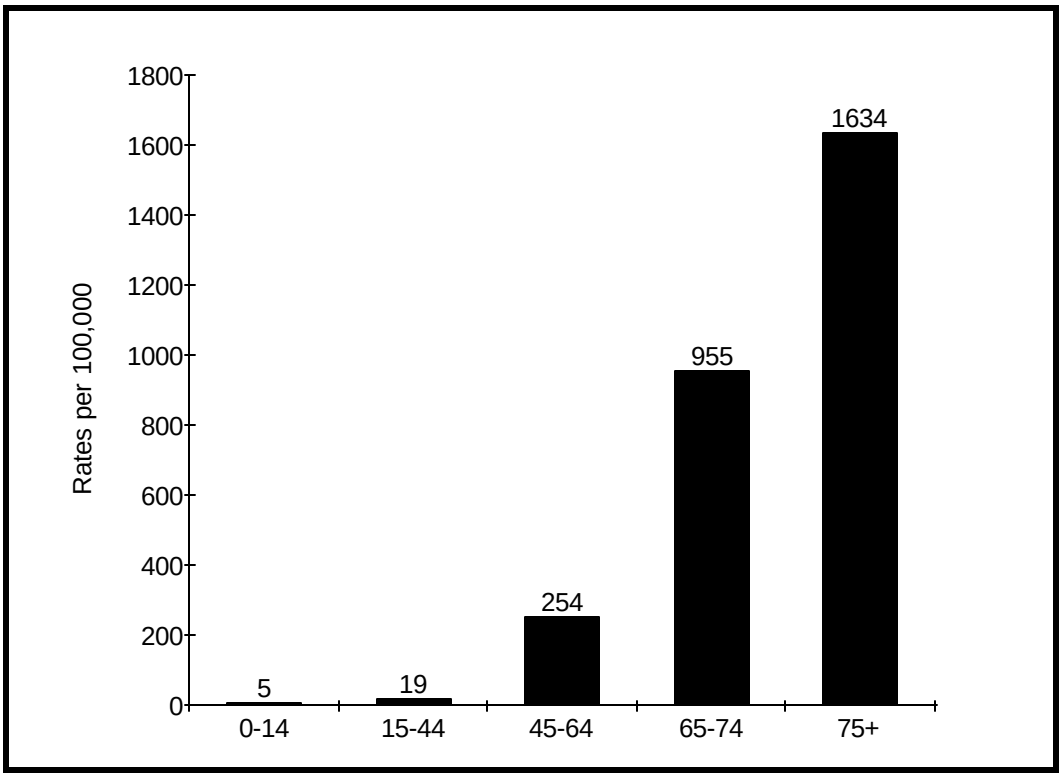
Certain factors impact the likelihood that a person will get cancer. Overall, African-Americans are more likely to develop cancer than persons of any other racial or ethnic group. In addition to race and ethnicity, increasing age increases the likelihood that a person will get cancer. We need to continue to improve our understanding of Maine's special populations, involve members of special populations in public health initiatives, and implement interventions that are appropriate for these groups.

Race and Ethnicity. Maine has a very small minority population compared to the United States. According to the 1998 population estimates, of the 1.2 million people living in Maine, only 8,963 people are Asian or Pacific Islanders, 8,929 are Hispanic, 6,321 are African-American, and 5,617 are Native American. While Maine's Native Americans live in every county in Maine and each of its cities, the vast majority resides in or near the five small, rural communities of Indian Island (Penobscot Nation), Pleasant Point (Passamaquoddy tribe), Indian Township (Passamaquoddy tribe), Houlton (Houlton Band of Maliseet) and Presque Isle (Aroostook Band of Micmac).[8]

In 1990, approximately 22 percent of the population was of Franco-American ancestry. After New Hampshire, Maine has the highest percentage of first- and second-generation Franco-Americans in the country. This group has tended to settle in the St. John River Valley in northern Maine and in textile and paper mill towns throughout the state.

Age. The risk of getting and dying from cancer increases dramatically with age (Figure 7). Maine has more older residents than in the U.S. as whole, and Maine's population is much older than it was even ten years ago. As Maine ages, with a doubling of our elder population during the next 20 years, the burden of cancer will increase.[9] Therefore it is important to use age-adjusted statistics when comparing Maine statistics over time or when comparing Maine data with other states. Although the risk of getting and dying from cancer increases dramatically with age, the behaviors and disease processes that result in cancer start much earlier.

Figure 7 Age-specific Cancer Death Rates, Maine, 1995-1996



Socioeconomic Status. The understanding of the link between socioeconomic status and cancer has expanded in the 1990s. In Maine, having less education has been associated with high rates of cigarette smoking, physical inactivity, and poor nutrition, which are factors associated with increased cancer risk.[10]

Factors That Impact Cancer Screening and Treatment in Maine

Certain factors influence whether people obtain regular cancer screenings and treatment. Risk factors for not obtaining screenings and treatment include low income, having no regular source of medical care, lack of a high school diploma, language barriers, lack of transportation, and living in a rural area.[11,12,13,14] Most of these factors are present in Maine.

Language and Education. Although Maine's minority population is only 1.7 percent of its total, language is still a significant barrier. Approximately 9 percent of Maine residents speak a language other than English at home;[15] many of these persons speak French.

Approximately 13 percent of Maine adults 25 years of age and older do not have a high school diploma; approximately 19 percent have completed a Bachelor's degree or more. Approximately 17 percent of United States adults do not have a high school diploma; approximately 24 percent have completed a Bachelor's degree or more.[16]

Income and Poverty. Even though Maine's poverty rate (percent of families below the poverty threshold which is an income of less than $16,660 for a family of four) is slightly lower than the U.S. rate (10.6 vs. 13.2 per 100,000, 1996-1998 average), the median household income in Maine is lower than the U.S. ($27,854 vs. $30,056).[17] This indicates that Maine households in general have less disposable

income than those in other states. In 1998, 10.4 percent of Maine's population was living in poverty, which equals 131,000 people.[18] Of the approximately 329,000 children living in Maine, 128,000 (38.3 percent) are at or below 200 percent of poverty.[19]

Insurance Status. It is estimated that approximately 145,000 Mainers are uninsured (12 percent of the population) and not covered by public or private insurance programs.[20] Of the approximately 329,000 children living in Maine, 18,000 (6 percent) are without health insurance.[21] Medicare provided coverage to approximately 210,000 Maine residents aged 65 and older in 1998. Medicaid provided coverage to 23,720 Maine residents in 1999 (excluding those receiving other coverage, such as Medicare).[22]

Rurality. Maine is New England's largest state and almost equal in land area to the other five New England states combined. It is the least densely populated state east of the Mississippi River; sixty-four percent of Maine's population lives in a rural area, as compared to 22.5 percent in the United States as a whole. Portland is Maine's largest city, with a 1990 population of 64,538. Only six other municipalities had populations over 20,000 in 1990; all but one are located in the southern half of the state.

Transportation. Maine has little traditional public transportation. Fourteen fixed-route transit systems provide regularly scheduled bus service in Maine. The systems in Maine's smaller cities and on two Indian reservations provide limited bus service, generally operating five or fewer days per week. Ferry services exist for the island communities, although for some of these islands, services are infrequent.

HIGHLIGHTS OF CANCER CONTROL IN MAINE

Organizations, professionals, and people interested in cancer prevention, control and care have been working for decades to help ease the burden of cancer in Maine. Much has been done by the Legislature, the Maine Bureau of Health (MBOH), voluntary health organizations, hospital-and health center-based programs, local public health departments, and statewide coalitions to reduce the burden of cancer in Maine. Following are some highlights of cancer prevention, control, and care efforts in Maine.

THE LEGISLATURE

A series of legislative and policy efforts have directed the Department of Human Services to take action to reduce cancer morbidity and mortality. These include:

The Cancer Prevention and Control Advisory Committee. In 1987, the state legislature established a cancer incidence registry, developed mandated reporting requirements for cancer incidence, and established the Cancer Prevention and Control Advisory Committee (CPACAC). The CPACAC serves as an advisory body to the MBOH on the operation of the Maine Cancer Registry and monitoring cancer incidence and mortality, and assists with the development of a coordinated statewide approach to cancer prevention and control.

Mandated Benefits Related to Cancer. The legislature has mandated benefits as part of individual and group insurance policies for screening mammography, prostate cancer screening, screening Pap test, and an annual gynecologic exam; required informed consent for breast cancer treatment options; and mandated coverage for reconstruction of both breasts after breast cancer surgery (see Summary of Maine Statutes regarding Cancer, Appendix B).

Smoke-free Legislation. The legislature mandated in 1993 that no smoking is allowed in enclosed places where the public is invited or allowed (restaurants are included in this law as of September 18,

1999; some exceptions apply regarding smoke shops, taverns, etc.), in any enclosed area of any hospital, in school buildings, and in areas where employees are doing work. (See Summary of Maine Tobacco Laws, Appendix C.)

The Fund for a Healthy Maine and the Partnership for a Tobacco-Free Maine. In June 1997, Maine passed landmark legislation increasing the cigarette excise tax from 37 cents to 74 cents per pack, creating the Fund for a Healthy Maine. Maine's tobacco control program, the Partnership for a Tobacco-Free Maine was also established from this legislation. (See Appendix A for a description of this program.) In November 1998, Maine signed on to the Master Settlement Agreement (MSA) that is a settlement between 46 states and the major tobacco companies. In 1999 and 2000, the Maine Legislature allocated $16.3 million of the tobacco settlement to the MBOH for the reduction of tobacco use and tobacco-related chronic diseases.

The Maine Bureau of Health

The MBOH is the state agency with primary responsibility for cancer prevention and control efforts. The Division of Community and Family Health (DCFH) is the division within the Maine Bureau of Health where programs aimed at health promotion and disease prevention programs are planned and implemented. Currently all cancer-related programs are now in the DCFH. Cancer and cancer-related programs in the DCFH include: the Maine Cancer Registry, the Maine Breast and Cervical Health Program, the Oral Health Program, the Partnership for a Tobacco-Free Maine, Public Health Nursing, and Children with Special Health Needs Program (see Appendix A for a description of these and other programs). In addition to these programs, the Community Health Promotion/Chronic Disease Prevention Program provides funds and technical assistance to 13 local community health promotion coalitions. Although to date these coalitions have not specifically dealt with cancer issues, they may choose to address these issues in the future. There are many other MBOH programs that are involved in some way in cancer prevention, control, and care, such as Health Engineering, and the HIV/STD prevention program, among others.

Voluntary Health Organizations

The American Cancer Society (ACS) in Maine has been a partner in efforts to reduce the impact of cancer in Maine for many years. ACS has played a key role in developing this Plan and has agreed to provide strong support in the implementation of this Plan. The American Lung Association (ALA) of Maine has been a leader in the fight against lung disease and has been a key partner in the efforts of the newly formed Maine Indoor Air Quality Council, the Smoking OR Health Coalition, and the Partnership for a Tobacco-Free Maine. This list is not exhaustive; many other voluntary health organizations have been active in various cancer prevention, control, and care efforts in Maine.

Statewide Coalitions

The Maine Coalition on Smoking OR Health has been responsible for much of the tobacco legislation that has been passed in the past ten to fifteen years. The goal of the coalition is to reduce tobacco use in Maine. The Maine Breast Cancer Coalition is committed to increasing public awareness of breast cancer; educating women and health care professionals about quality care, including early detection, management, and treatment options; advocating for legislative action; and developing support services for women facing the challenge of breast cancer. This list is not exhaustive; many other statewide coalitions have been active in various cancer prevention, control, and care efforts in Maine, such as the Maine Children's Cancer Program and the Maine Consortium for Palliative and Hospice Care. There are also many local coalitions that have been involved in cancer prevention, control, and care, such as the local Breast and Cervical Health coalitions and the Healthy Community coalitions.

MAINE'S PUBLIC HEALTH SYSTEM

Maine's public health system is very different from many other states in that it does not have a typical public health infrastructure. Since Maine is composed primarily of small towns, local health departments are nonexistent except in the larger cities. Portland, Maine's largest city, has a very active and innovative public health department. Bangor and Lewiston/Auburn, two other larger municipalities, have less active public health departments. There are no county health departments. A small number of MBOH staff provide health-related services in regional offices of the Maine Department of Human Services. These functions are limited to public health nurses, who make home visits and run immunization and well-child clinics, and health engineers, who do inspections. The MBOH has, however, developed an effective strategy of collaborating with the private sector to deliver health care and preventive services.

Most public health services are contracted by the MBOH to community-based agencies at the local level. Public health efforts such as disease prevention and control are carried out through public/private/voluntary partnerships with the MBOH. This model has been extremely successful. Health promotion and education activities are delivered through cooperative efforts with local networks and coalitions, while the MBOH provides guidelines, public and professional education, quality assurance, and technical assistance.

SCREENING AND DIAGNOSIS

Cancer screening is generally initiated by a primary care provider who performs clinical breast exams and screening tests for cervical cancer, prostate cancer, colorectal cancer, and other cancer tests as needed. They provide instruction in self-breast exam and refer people when appropriate for other cancer screenings that cannot be conducted in their office, such as mammography or sigmoidoscopy. The health care system in Maine is predominantly private with over 900 primary care physicians in practice.[23] Rural community health centers, family planning clinics, and hospital-based family practice residency programs provide health care, including cancer screening, to all patients regardless of their ability to pay, providing a sliding fee scale to accommodate the medically indigent. In some areas of the state, low-income residents seeking screening services may not have access to rural health centers and family planning clinics that offer sliding fee scale services and may have difficulty accessing a private practice provider.

CANCER TREATMENT

There are currently 10 American College of Surgeons (ACoS)-approved hospital cancer treatment centers throughout Maine, including the following institutions:

Augusta	MaineGeneral Medical Center
Bangor	Eastern Maine Medical Center
Biddeford	Southern Maine Medical Center
Lewiston	Central Maine Medical Center
Lewiston	St. Mary's Regional Medical Center
Portland	Maine Medical Center
Rockport	Penobscot Bay Medical Center
Skowhegan	Redington-Fairview General Hospital
Togus	VA Medical Center
Waterville	MaineGeneral Medical Center

Having ACoS approval certifies that a hospital has the following:

- Multidisciplinary cancer committee – providing program leadership for the institution.
- Cancer conferences – to ensure that interdisciplinary consultation is available for each patient case.
- Patient care evaluation – completing two patient care evaluation studies each year.
- Tumor registry – to track information about all malignancies that are diagnosed or treated in the institution.

COMPREHENSIVE CANCER PLANNING IN MAINE

Much has been done by the Legislature, the Maine Bureau of Health (MBOH), voluntary health organizations, hospital- and health center-based programs, local public health departments, and statewide coalitions to reduce the burden of cancer in Maine. This cancer control effort recognizes and builds upon these efforts while acknowledging that many of these efforts have addressed only one particular type of cancer, such as breast or lung cancer, or one approach, such as prevention or early detection, and that a comprehensive and integrated approach to cancer control is needed to provide greater improvement. For this planning process, comprehensive cancer control was defined as a coordinated and integrated approach to reduce cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation.[24]

In March 1998, the MBOH was selected by the Centers for Disease Control and Prevention (CDC) as a model planning state for comprehensive cancer control. Along with five other states, Maine's comprehensive planning process would be documented and evaluated by the CDC and the Battelle Centers for Public Health Research and Evaluation in order to develop a model for all states to use as they develop their own comprehensive cancer control programs.

THE CONSORTIUM

In April 1999, MBOH staff organized the first comprehensive cancer control planning meetings in Bangor and Portland. Representatives from public and private organizations involved in all areas of cancer prevention, control and care were invited to become involved in this planning effort. Although the MBOH made every effort to make this planning process inclusive, gaps in participation may exist and will be resolved as they are identified.

The Maine Consortium for Comprehensive Cancer Control (hereafter referred to as the Consortium) was developed as a result of this planning process. The mission of the Consortium is to reduce the burden of cancer in Maine by working collaboratively to optimize access to care, prevention, early detection, treatment, rehabilitation, survivorship, palliative, and quality-of-life services.

The Consortium began a systematic planning process to determine how best to achieve their mission. Work Groups were established to focus on specific areas of cancer and have worked over the past year to develop goals, objectives, and strategies for accomplishing comprehensive cancer control and care in Maine.

Specifically, the goals of the Consortium are to build a comprehensive cancer prevention, control, and care infrastructure that will:

- Increase statewide integration, coordination, and provision of quality prevention, detection, treatment, rehabilitation and survivorship, palliative, and hospice care services in Maine.
- Increase access to high-quality cancer prevention, detection, treatment, rehabilitation and survivorship, palliative, and hospice care information and services for all Maine residents regardless of geographic, financial, and other demographic factors.
- Increase the proportion of Maine residents who appropriately utilize screening, follow-up, treatment, rehabilitation, survivorship, hospice and palliative care services.
- Improve the quality and coordination of cancer surveillance and other data systems and the extent to which these and other evaluation data are used for comprehensive cancer control programming and management.
- Increase support from policy and grant makers for comprehensive cancer control in Maine.

Specific, measurable objectives have been developed by the Work Groups to achieve these goals, and they are the foundation of this Plan. (These are discussed in detail in Sections I through VI of the Plan.)

THE COMPREHENSIVE CANCER CONTROL PLAN

The Maine Comprehensive Cancer Control Plan (hereafter referred to as the Plan) is the work of many people. Data, resources, and previous cancer prevention and control planning efforts have been reviewed; experts in the field have shared their experiences and recommendations. Numerous discussions have taken place to determine which cancer sites and issues need to be focused on, which ones are capable of being addressed, and which evidence-based strategies have been shown to be the most effective in addressing these issues. The planning efforts of other programs and organizations (such as the American Cancer Society, the Maine Breast and Cervical Health Program, the Maine Consortium for Palliative Care and Hospice, Healthy Maine 2000, and others) have been incorporated into this plan. Experts in the fields of cancer prevention, control, and care have met in various Consortium Work Groups and have written and/or reviewed various sections of this Plan. (A list of Work Group members appears at the beginning of each section). The Consortium intends to conduct ongoing evaluation and subsequent revisions of this Plan annually.

The vision of the Plan is to dramatically improve the well-being of Maine's citizens; to reduce the human suffering and economic burden caused by cancer in Maine; and to eliminate, to the extent possible, the differences in how cancer affects Maine's population groups.

This vision will be achieved through specific, statewide, regional, and local action. The Plan describes in detail actions to be taken over the next 5 years for high-priority activities in primary prevention, early detection, treatment, rehabilitation and survivorship, palliative, and Hospice care. It identifies specific roles for unified and separate, but coordinated, action by government, the private sector, the non-profit sector and Maine's communities and citizens. This Plan incorporates the diverse views of people and organizations from throughout the state and identifies both environmental and individual areas that can be affected by intervention.

This Plan is a working document to be used to guide current and future coordinated efforts in comprehensive cancer prevention, control, and care. Once implemented, this Plan will reduce the burden of cancer in Maine.

Primary Prevention

PRIMARY PREVENTION WORK GROUP MEMBERS

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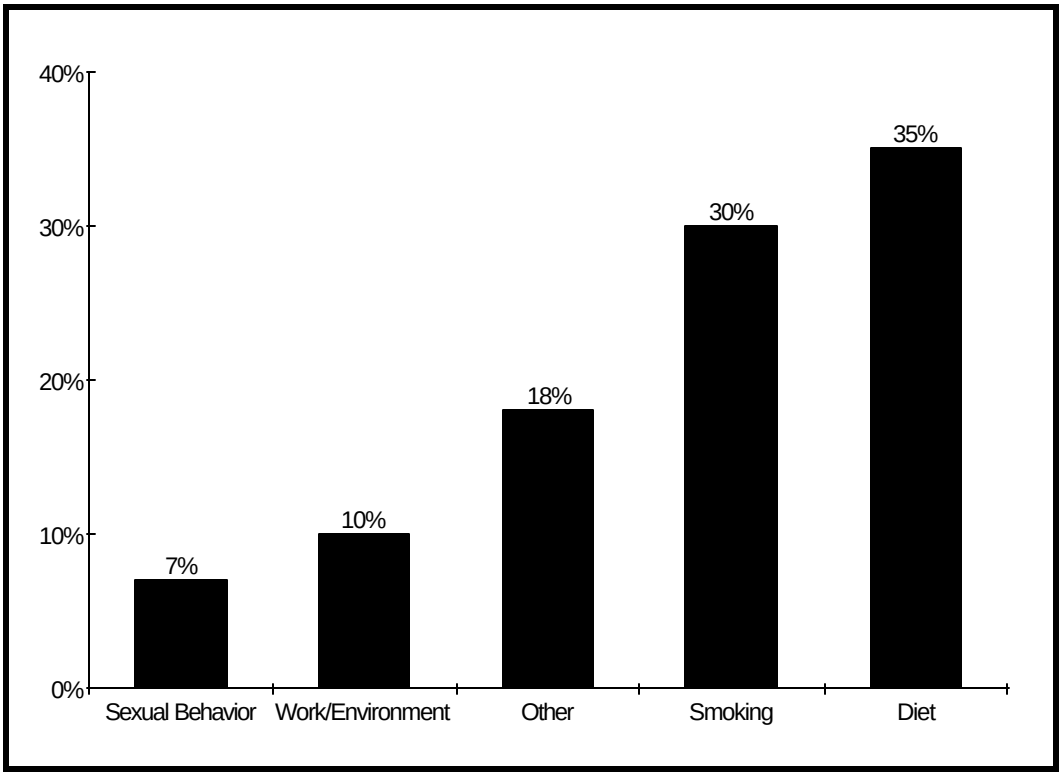
***Work Group Chairs**

PRIMARY PREVENTION

Some cancers are directly associated with a cancer-causing agent such as tobacco in the case of lung cancer. Other cancers, such as colorectal, skin, and cervical cancer, have also been linked to preventable factors. Scientific evidence suggests that about one-third of cancer deaths are related to nutrition and other lifestyle factors and could be prevented (Figure 8). Certain cancers are related to viral infections such as hepatitis B and human papillomavirus and could be prevented through behavioral change. In addition, many skin cancers can be prevented by protection from the sun's rays.[25] Primary prevention of cancer can be defined as those actions that can be taken by individuals, communities, government, or other groups to prevent the occurrence of cancer through health-promoting lifestyle choices and through control of environmental health and societal risk factors.

Figure 8 Proportion of Preventable Cancer Attributed to Various Factors



Source: Doll and Peto, 1981

Cancer is believed to be the final outcome of a series of events that occur over time, moving from a precancerous stage to fully developed invasive cancer. Cancer may be avoided by modifying risk factors so that the start or progression of the disease is prevented. The mission of the Prevention Work Group is to identify gaps in current cancer prevention activities and develop strategies to improve cancer prevention. The Prevention Work Group has identified tobacco use, nutrition and physical activity, exposure to ultraviolet radiation, sexual health, and exposure to environmental and occupational carcinogens as priority areas on which to focus over the next five years. The following is a brief discussion of the goals and objectives developed for these priority areas.

TOBACCO USE

Tobacco causes cancer of the lung, trachea, and bronchus, bladder, kidney, lip, pharynx, esophagus, oral cavity, larynx, pancreas, nose, stomach, and liver and also causes myeloid leukemia. Tobacco may also cause cervical cancer, but there is still scientific controversy about this relationship.[26,27,28,29,30]

An estimated 156,900 people will die from lung cancer in the United States in 2000, accounting for 28 percent of all cancer deaths. During 1992-1996, mortality from lung cancer declined significantly among men while rates for women were still significantly increasing. In the United States, approximately one-half of all continuing smokers die in middle age (35-69 years of age), losing an average of 20-25 years of life expectancy. In addition, secondhand smoke, also known as environmental tobacco smoke (ETS), has been determined by numerous scientific bodies to be a human carcinogen for which there is not a safe level of exposure. ETS contributes to lung cancer, heart disease, and other respiratory problems in nonsmokers.[31]

Lung cancer incidence and mortality rates in Maine are higher than the corresponding U.S. rates (Figures 9 and 10). Lung cancer is the leading cause of cancer deaths in Maine. Approximately 1,000 Mainers will die from lung cancer in 2000.[32]

Figure 9 Comparison of Lung and Bronchus Cancer Incidence Rates for Maine and the United States

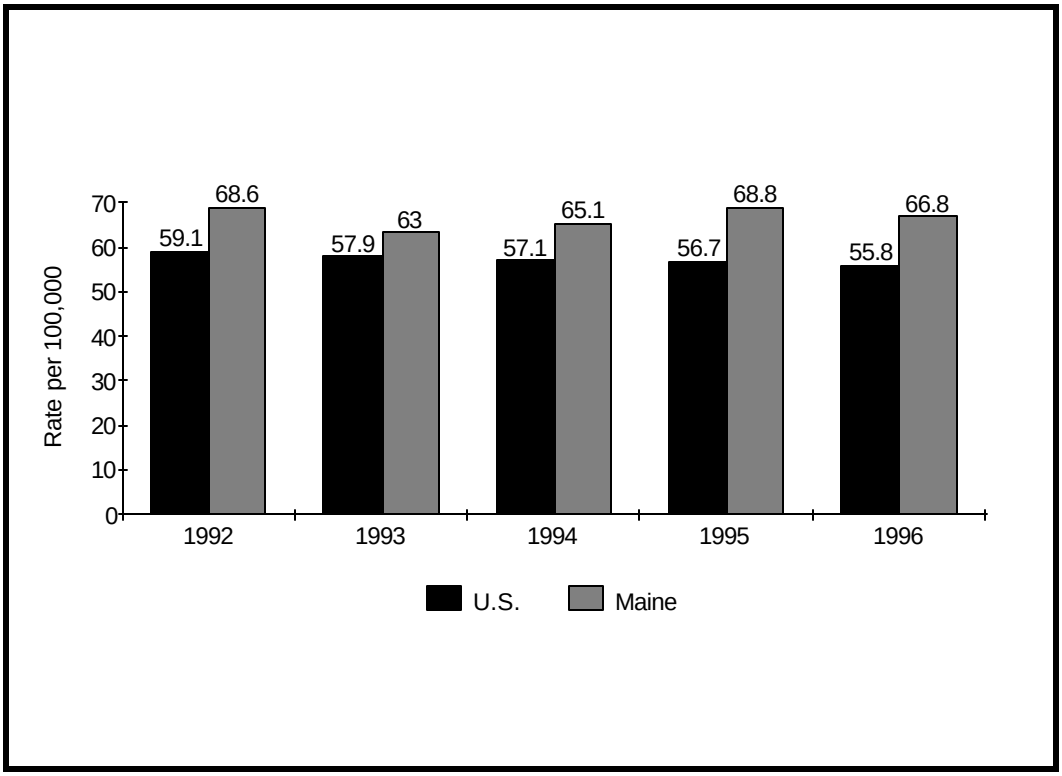
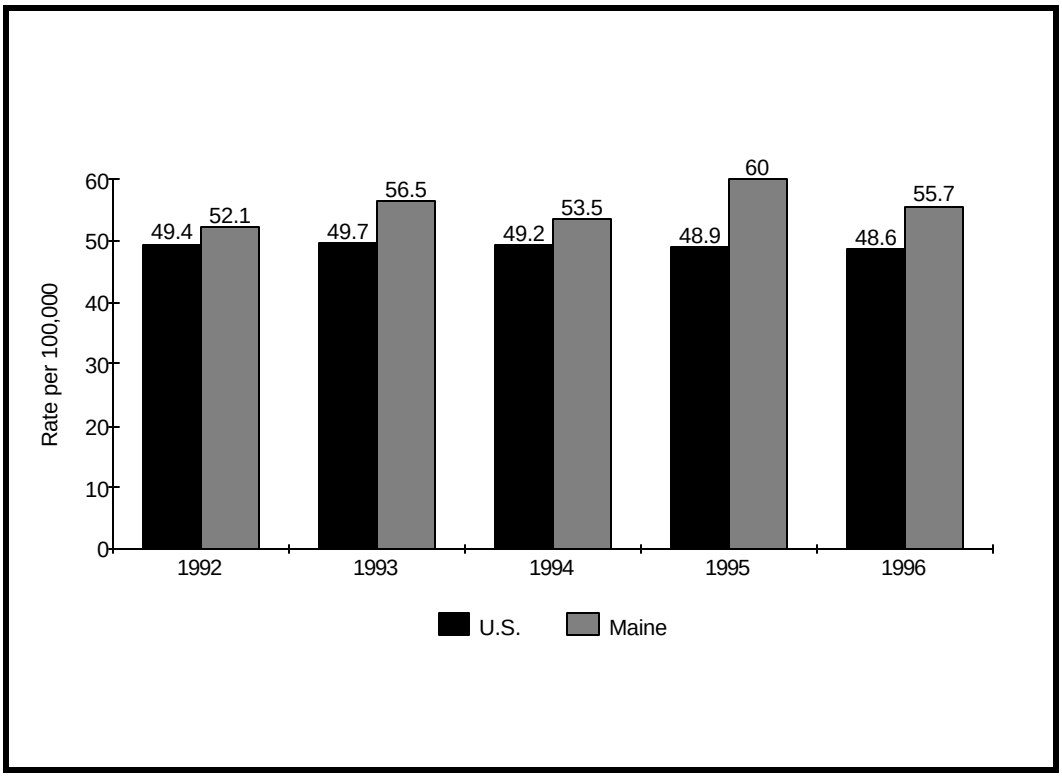


Figure 10 Comparison of Lung and Bronchus Cancer Mortality Rates for Maine and the United States



Lung cancer incidence and mortality rates are higher for Maine males than females (Figures 11 and 12). Over a 12-year period (1983-1994), however, female lung cancer incidence rates showed a 44 percent increase and female lung cancer mortality rates increased 64 percent.[33]

Figure 11 Comparison of Lung and Bronchus Cancer Incidence Rates for Maine Men and Women

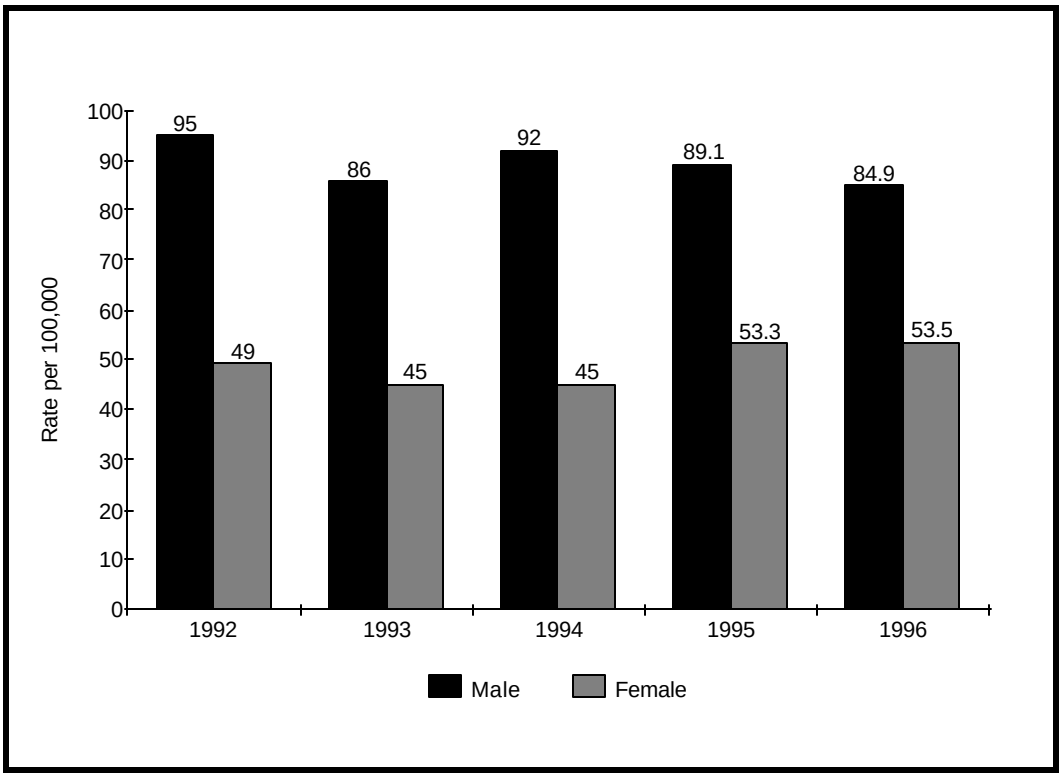
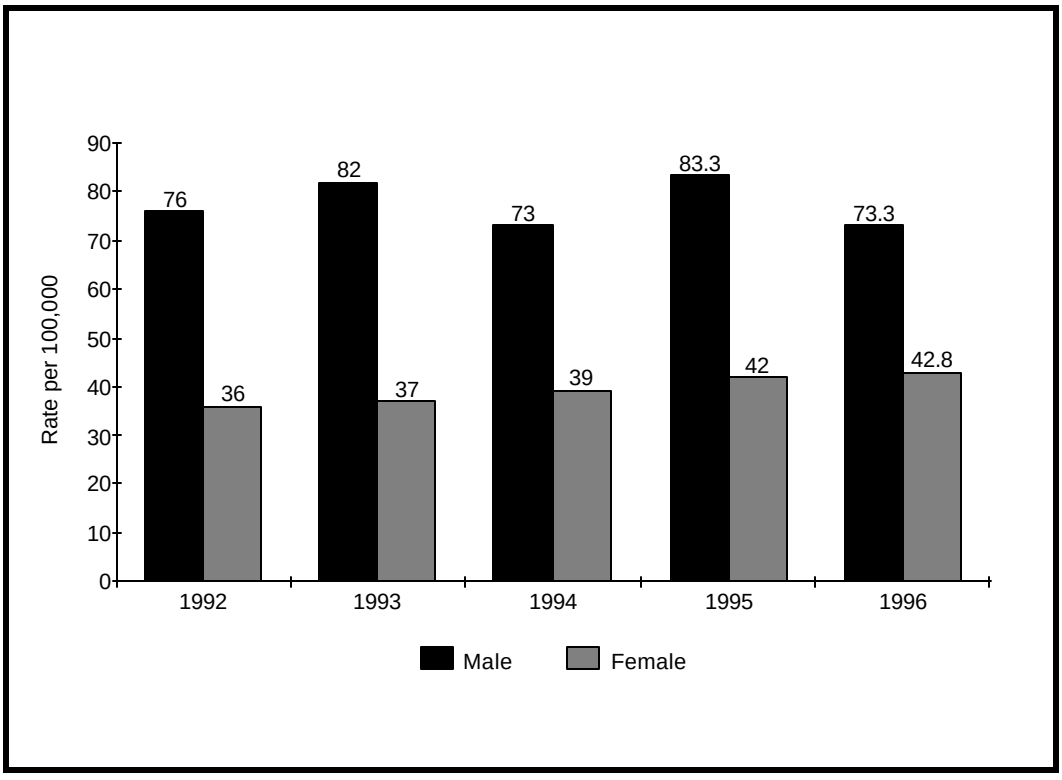


Figure 12 Comparison of Lung and Bronchus Cancer Mortality Rates for Maine Men and Women



Tobacco use among adult Mainers is about the same as for the nation (22.7 percent).[34] The Maine youth smoking rate (22.1 percent), however, is higher than the United States rate (19.2 percent). Maine ranks sixth highest in the nation and first among New England states for teen smoking rates. The Maine teen smoking rate is very close to the adult rate and may soon exceed the adult rate, which is not good for the future.[35]

GOAL 1: To significantly reduce the initiation of tobacco use, to increase the numbers who successfully quit using tobacco, and to reduce exposure to secondhand smoke

Objective 1.1

Reduce the proportion of Maine adults aged 18 and older who use tobacco products to 15 percent by 2005. [Maine baseline: 22 percent, Behavioral Risk Factor Surveillance System (BRFSS), 1998.]

Strategies

- Implement community-based tobacco prevention and control programs statewide that engage local organizations, schools, youth, parents, enforcement officials, community and business leaders, and health care providers.
- Promote governmental and voluntary policies to promote clean indoor air, restrict access to tobacco products, provide insurance coverage for treatment, and other policy objectives.
- Continue to implement a statewide media campaign to counter pro-tobacco influences and increase pro-health messages and to promote smoking cessation.
- Establish a statewide telephone cessation help line, increase availability of effective cessation programs, and promote policies that cover treatment of tobacco use under public and private insurance.

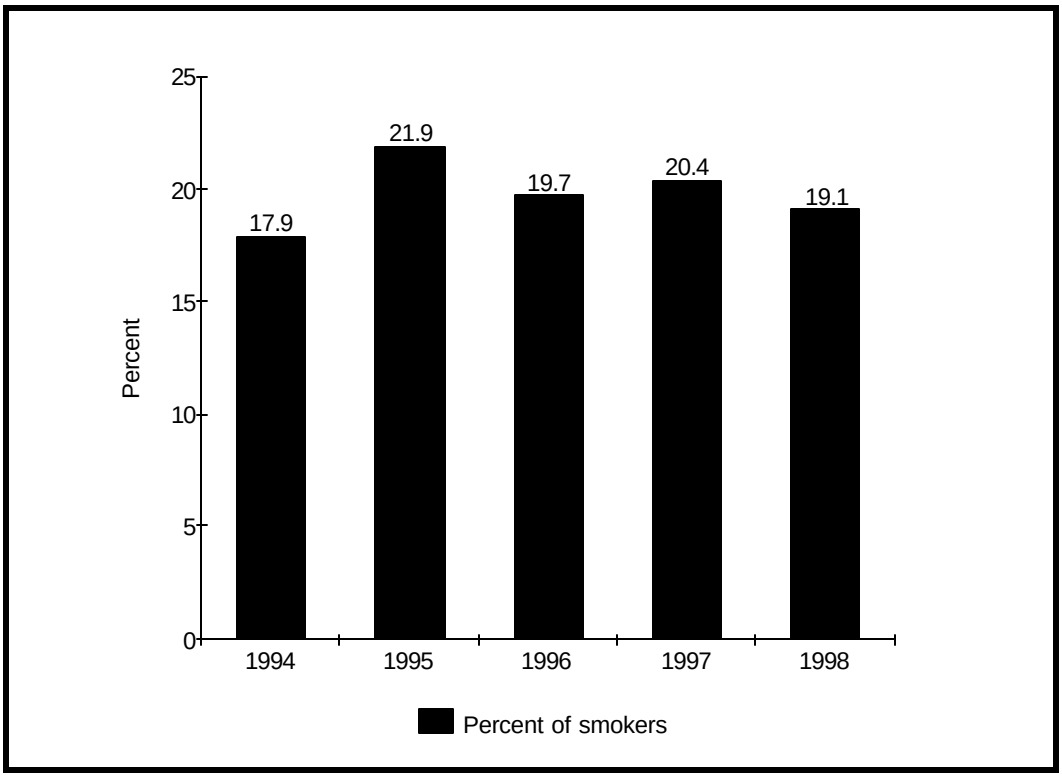
Objective 1.2

Reduce cigarette smoking among pregnant women to 15 percent by 2005. [Maine baseline: 19.1 percent of pregnant women surveyed smoked, Pregnancy Risk Assessment and Monitoring System (PRAMS), 1998, Figure 13.]

Strategies

- Implement health care provider-based education and patient counseling programs for pregnant women.
- Provide accessible, affordable, and proven cessation programs statewide for this population.

Figure 13 Proportion of Maine Women Who Smoke During Pregnancy, 1994-1998



Source: Pregnancy Risk Assessment and Monitoring System, Maine Department of Human Services.

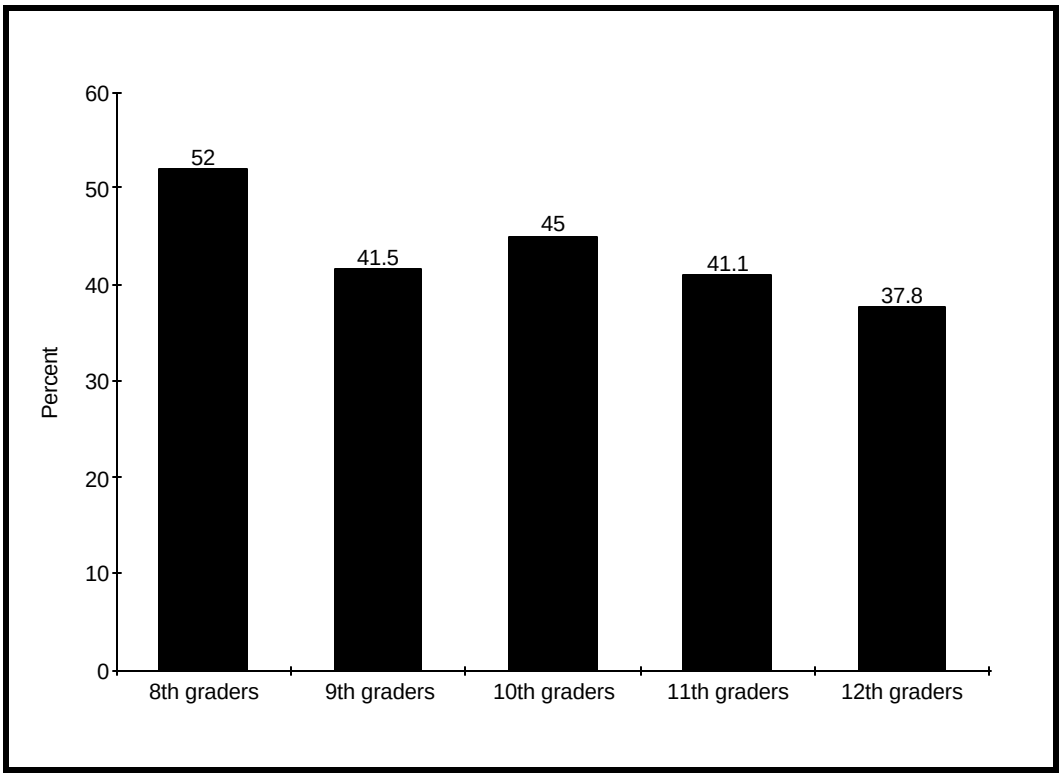
Objective 1.3

Increase the proportion of young people who have never smoked to 60 percent for 8th graders and 45 percent for 12th graders by 2005. [Maine baseline: 51 percent of 8th graders and 37.8 percent of 12th graders report they have never tried smoking, Youth Risk Behavior Survey (YRBS), 1999, Figure 14.]

Strategies

- Implement effective community based programs (such as the "Tar Wars" Program offered by the Maine Academy of Family Physicians) statewide that engage youth in developing and implementing tobacco control interventions and that include teacher training and parental involvement.
- Implement evidence-based curricula identified through CDC's Research to Classroom Project and promote comprehensive school health education.
- Promote and assist schools in adopting and enforcing tobacco-free policies.
- Provide accessible, affordable and proven cessation programs for youth.
- Continue to implement a statewide media campaign to counter pro-tobacco influences and increase pro-health messages.
- Enforce laws that restrict minors' access to tobacco products.

Figure 14 Proportion of Maine Youth Who Have Never Smoked, 1999



Source: Maine Youth Risk Behavior Survey, Maine Department of Education.

Objective 1.4

Increase the proportion of patients who receive advice to quit smoking each year from a health care provider.

Strategies

- Work with health care providers to develop systems that will increase the number of patients who receive brief advice, counseling, and pharmacotherapy from medical providers per the Agency for Healthcare Research and Quality Guidelines.
- Provide training to providers on smoking cessation.
- Encourage insurance coverage of cessation treatment

Objective 1.5

Eliminate involuntary public exposure to environmental tobacco smoke (ETS) for all Maine citizens.

Strategies

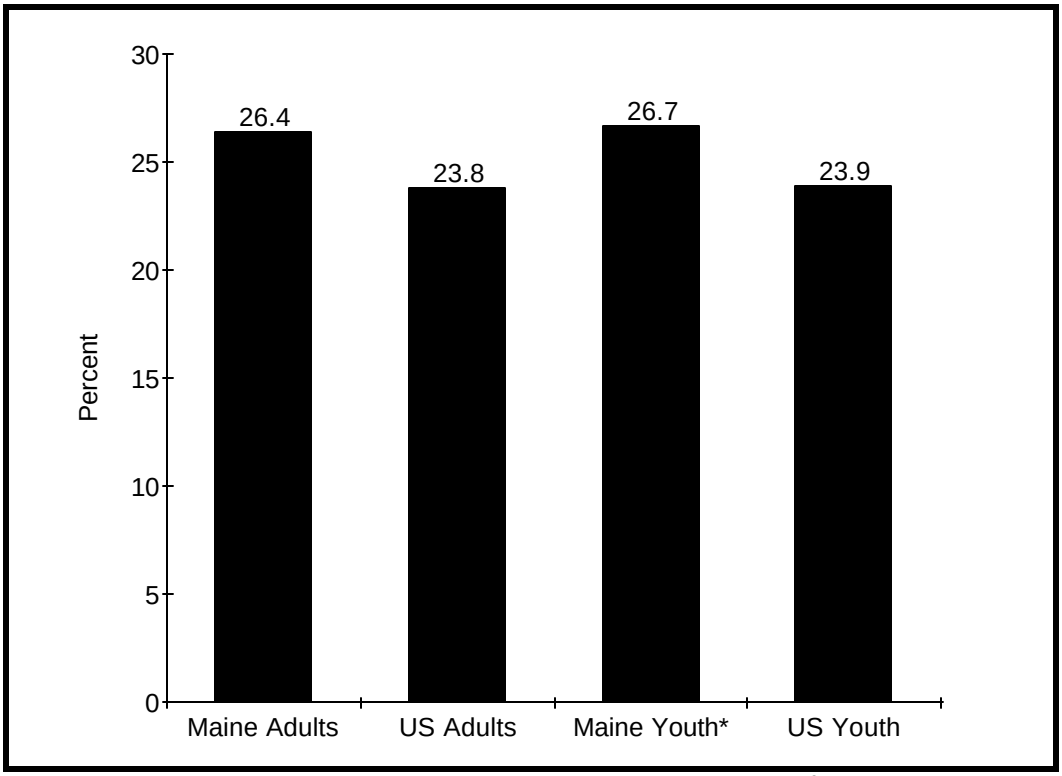
- Promote state and local policies, including voluntary policies that restrict smoking in all public places.
- Increase awareness of the harmful effects of ETS to children exposed in schools, daycares, homes, automobiles, and public places.
- Increase enforcement and monitor compliance with existing clean indoor air laws.

NUTRITION AND PHYSICAL ACTIVITY

Scientific evidence suggests that about one-third of cancer deaths are related to nutrition and other lifestyle factors and therefore are preventable. (See Appendix D for sources such as the National Cancer Institute and American Cancer Society that have developed dietary recommendations to reduce cancer risk.) For Americans who do not use tobacco, dietary choices and physical activity become the most important modifiable determinants of cancer risk.[36] Diets high in fat have been linked to increased risk of various cancers, particularly breast, colon, prostate, and possibly pancreas, ovary, and endometrium. The incidence of some cancers can be reduced by maintaining lean body weight and engaging in regular moderate to intense physical activity. Physical inactivity is a possible risk factor for colorectal cancer and is being studied to see if it is a risk factor for breast cancer.[37]

Only 24.1 percent of Maine adults report regular physical exercise.[38] Twenty-six percent of Maine adults and 27 percent of Maine youth report eating five or more fruits and vegetables daily (Figure 15).[39] Improved diet and increased physical activity can also reduce death and disability from other chronic diseases, particularly cardiovascular disease and diabetes.

Figure 15 Proportion of Maine Adults and Youth Eating Five Servings a Day of Fruits and Vegetables



Source: Behavioral Risk Factor Surveillance System, 1998, Maine Department of Human Services; Youth Risk Behavior Survey, 1999 (*Unweighted data), Maine Department of Education.

GOAL 2: To reduce the risk of colorectal and other cancers through healthful eating habits and physical activity.

Objective 2.1

Increase the proportion of persons who eat five servings of fruits and vegetables daily to 30 percent of adults and 35 percent of high school students by 2005. (Maine baseline: 26.4 percent of adults greater than or equal to 18 years of age consumed at least five servings of fruits and vegetables daily, BRFSS, 1998; 26.7 percent of high school students consumed at least five servings of fruits and vegetables daily, YRBS, 1999).

Strategies

- Work with schools to strengthen the nutrition and physical activity components of Comprehensive School Health Education and Coordinated School Health Programs statewide.
- Implement effective community-based programs statewide that address one or more of the Dietary Guidelines for Americans.
- Promote governmental and voluntary policies that support the recommendations of the Food Guide Pyramid.
- Advocate for reimbursement of preventive nutrition counseling by public and private health insurance providers.

Objective 2.2

Increase the proportion of adults who engage regularly, preferably daily, in sustained physical activity for at least 30 minutes per day to 30 percent by 2005. (Maine baseline: 24.1 percent of adults age 18 and older, BRFSS, 1998.)

Strategies

- Implement successful worksite model programs statewide to promote physical activity (e.g., the March Into May Program).
- Implement effective community-based programs statewide that promote daily physical activity.
- Promote governmental, state, voluntary, and local policies that promote daily physical activity.
- Ensure that adequate opportunities for safe physical activity are available (e.g., green spaces, community recreation facilities, walking trails, and safe sidewalks).

Objective 2.3

Increase the proportion of young people who engage in vigorous physical activity three or more days per week for 20 minutes or more per occasion to 75 percent by 2005. (Maine baseline: 70.6 percent of high school students surveyed; YRBS, 1999.)

Strategies

- Initiate the adoption of daily physical education in schools statewide (grades K-12).
- Implement community-based programs for young people statewide to engage in vigorous physical activity.
- Promote governmental, state, voluntary, and local policies that promote daily physical activity.

Objective 2.4

Decrease the proportion of adults who are overweight to 50 percent by 2005. (Maine baseline: 53.2 percent of adults age 18 and older are overweight based on Body Mass Index of greater than or equal to 25, BRFSS, 1997.)

Strategies

- Same as for Objectives 2.1, 2.2, and 2.3.

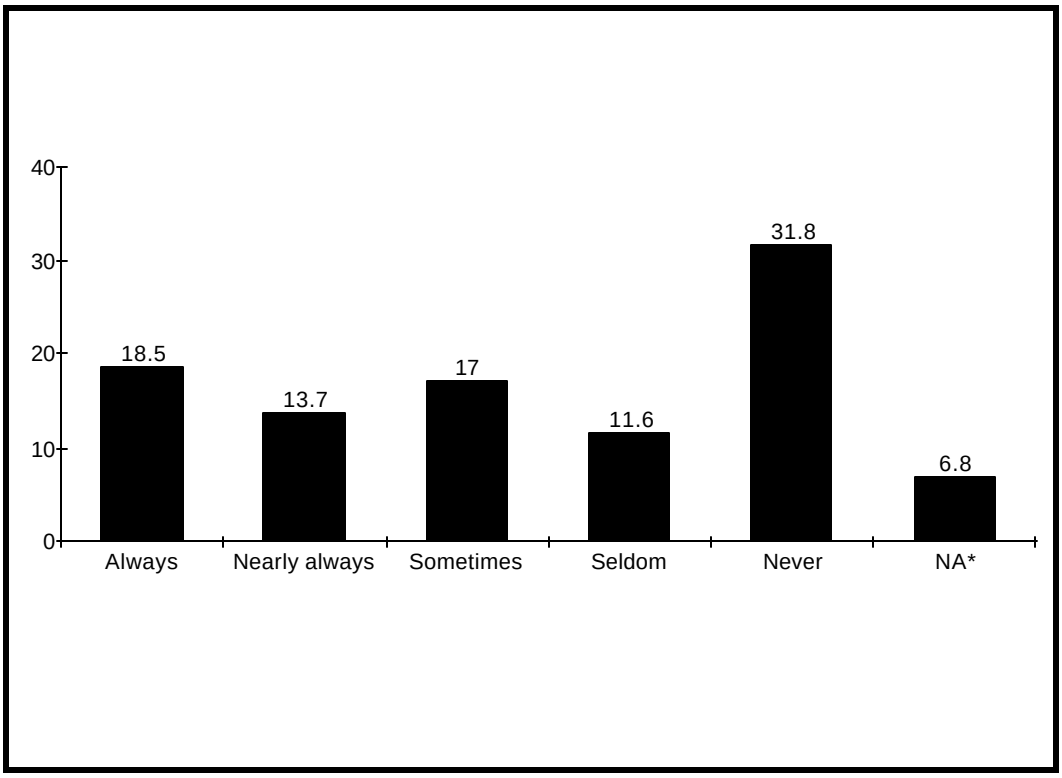
EXPOSURE TO ULTRAVIOLET RADIATION

Approximately 1.3 million new cases of highly curable basal cell or squamous cell cancers are diagnosed each year in the United States. These cancers are more common among people with lightly pigmented skin. Melanoma, the most serious form of skin cancer, has increased significantly in the United States from 1973 to 1996. Incidence rates are more than 10 times higher in whites than in blacks.[40]

It is estimated that in 2000, 200 people in Maine will be diagnosed with melanoma and approximately 30 will die from this most serious form of skin cancer.[41] Most of these cancers could be prevented by protection from the sun's rays. Few Maine adults limit sun exposure, wear protective clothing, or use sunscreen (Figure 16). In 1999, 32 percent of Mainers "always" or "nearly always" used sunscreen; 30 percent "always" or "nearly always" stayed in the shade; and 37 percent "always" or "nearly always" wore a hat when outside on a sunny summer day for more than an hour. (See Appendix D for sources that have developed sun exposure guidelines.)

Artificial sources of ultraviolet radiation also contribute to skin cancer. Eleven percent of Mainers report using sunlamps or tanning booths. Of these, 84 percent report using sunlamps or tanning booths seasonally, 8 percent use them monthly and 8 percent use them weekly.[42]

Figure 16 Proportion of Maine Adults Who Use Sunscreen



Source: Behavioral Risk Factor Surveillance System (*NA = don't stay out more than an hour), 1999, Maine Department of Human Services.

GOAL 3: To reduce the incidence of skin cancer in Maine.

Objective 3.1

Increase the proportion of Maine adults aged 18 and older who "always" or "nearly always" stay in the shade when outside on a sunny summer day for more than an hour to 35 percent by 2005 (Maine baseline: 7.6 percent of adults "always" and 22.1 percent "nearly always" stay in the shade, BRFSS, 1999).

Strategies

- Implement media and community-based programs to promote and educate the public on the benefits of sun protection. Utilize existing proven programs like "Slip, Slop, Slap" and "Choose Your Cover."
- Focus efforts on occupational groups statewide that are at increased risk due to time working outdoors including fishermen, farmers, and public works employees.
- Work with health care providers to promote education and counseling to clients regarding sun protection.
- Implement Comprehensive School Health Education (CSHE) and Comprehensive School Health Programs (CSHP) statewide in grades K-12.

Objective 3.2

Increase the proportion of Maine adults aged 18 and older who "always" or "nearly always" wear a hat when outside on a sunny summer day for more than an hour to 45 percent by 2005. (Maine baseline: 24.0 percent of adults "always" and 13.3 percent "nearly always" wear a hat, BRFSS, 1999.)

Strategies

- Same as for Objective 3.1.

Objective 3.3

Increase the proportion of Maine adults aged 18 and older who "always" or "nearly always" use sunscreen to 40 percent by 2005. (Maine baseline: 18.5 percent "always" and 13.7 percent "nearly always" use sunscreen, BRFSS, 1999.)

Strategies

- Same as for Objective 3.1.

Objective 3.4

Reduce the proportion of Maine adults aged 18 and older who use artificial sun tanning and other sources of ultraviolet light to 5 percent by 2005. (Maine baseline: 11 percent use sunlamps or tanning booths, BRFSS, 1999.)

Strategy

- Utilize community-based programs and policies to promote the dangers of artificial sun tanning through health clubs, workplaces, schools, and the media

Objective 3.5

Increase public awareness of ozone depletion and its relationship to skin cancer.

Strategy

- Support efforts of organizations that work to inform public policy to reduce ozone depletion.

SEXUAL HEALTH

Sexual behavior has been identified as the primary risk factor for cervical cancer. Risk increases for women reporting early age at first intercourse or multiple sexual partners throughout their life. Certain types of human papillomavirus (HPV), the most common sexually transmitted disease (STD) in the U.S., are associated with the development of cervical, vulvar, anal, and penile cancers. Recent evidence links HPV with oral cancer as well. Despite the increasing public health concern of HPV, no prevention programs have been established and few Americans are aware of HPV. Seventy percent of Americans have not heard of HPV and only 5 percent report ever having discussed HPV with a health care provider.[43] Other agents that are transmitted sexually and are associated with cancer include Hepatitis B

Virus (HBV) and Human Immunodeficiency Virus (HIV). HBV is associated with liver cancer and HIV is associated with Non-Hodgkin's Lymphoma, Kaposi's Sarcoma, and other malignancies.

Currently early detection is the standard for prevention of cervical cancer. However, with new technologies emerging for HPV-testing, the development of effective HPV vaccines, the lack of knowledge about HPV among the general public, and the availability of non-vaccine modalities for primary prevention of HPV infection, the next few decades may see a shift toward primary prevention of cervical cancer. Additionally, methods used to prevent other STDs will have some impact on reducing the incidence of HPV infection and, indirectly, the incidence of cervical cancer.

GOAL 4: To reduce the risk of cervical and other cancers associated with sexual activity.

Objective 4.1

Reduce the incidence of sexually transmitted infections in Maine that are associated with the development of cancer, including HPV, HBV, and HIV. (Maine baseline: HBV: 5 cases, HIV: 32 cases, HPV: not a reportable infectious disease, Maine Bureau of Health, Division of Disease Control, 1998.)

Strategies

- Promote updated education of health care providers and family planning professionals about HPV-prevention messages, developments in testing and treatment, vaccine developments, and patient counseling for sexually active patients, especially those with HPV infection and their partners. Use existing newsletters and conferences to provide information and training.
- Promote public knowledge about HPV through individualized counseling or health education messages delivered at the community level with targeted key HPV messages by providers.
- Implement Comprehensive School Health Education (CSHE) and Comprehensive School Health Programs (CSHP) for grades K-12, including school-based health centers, statewide.
- Fully implement HIV- and STD-prevention strategies that target specific intervention strategies at high-risk groups.
- Evaluate current HIV- and STD-prevention strategies that target high-risk groups and use results to develop more efficacious behavioral change interventions.
- Conduct public education to promote condom use as a social/community norm and increase condom availability and access. Target these efforts at people initiating sexual activity and those at high risk for STD.
- Increase knowledge and availability of new safer sex technologies including microbocides and the female condom which give female partners increased control over safer sex decisions.
- Promote HIV antibody counseling, testing, partner counseling, and referral services for individuals at high risk of HIV infection.
- Promote early access to treatment for HIV-seropositive individuals.

Objective 4.2

Increase safe sex practices including: reducing the number of sexual partners, selecting partners who have had a fewer number of partners, delay of early onset of sexual activity, increasing condom use, and abstinence. (Maine baseline: 20 percent of 7th graders and 71 percent of 12th graders had sexual intercourse; 51 percent of currently sexually active high school students used condoms, YRBS, 1997.)

Strategies

- Implement CSHE and CSHP, including school-based health centers, statewide for grades K-12.
- Conduct public education to promote condom use as a social/community norm and increase condom availability and access. Target these efforts at people initiating sexual activity and those at high risk for STD.
- Increase knowledge and availability of new safer sex technologies including microbocides and the female condom which give female partners increased control over safer sex decisions.

Objective 4.3

Promote and increase Hepatitis B immunizations for all children by the time they become sexually active (recommended by age 10) and for adults at risk of infection. (Maine baseline: 87 percent of children 19-35 months of age have received a complete HBV series, United States National Immunization Survey, 1999.)

Strategies

- Evaluate the current childhood-HBV vaccination program to identify areas of need. Based on the findings, develop and implement educational strategies to increase childhood-HBV vaccination.
- Assess adult populations at risk for HBV infection in Maine. Fully fund and implement HBV vaccination for all at-risk adults.

EXPOSURE TO ENVIRONMENTAL AND OCCUPATIONAL CARCINOGENS

About 20 chemicals found in the environment (including arsenic, asbestos, benzene, cadmium, chromium, radon, and vinyl chloride) have been identified as known human carcinogens by agencies such as the World Health Organization's International Agency for Research on Cancer, the U.S. National Toxicology Program, the National Cancer Institute, and the U.S. Environmental Protection Agency (EPA). Many additional chemicals have been identified as being potential human carcinogens. The cancer burden posed by specific environmental carcinogens (aside from occupational exposures), however, has in general not been well defined. The percent of annual cancer deaths thought to result from all environmental pollution has been estimated at about 2 percent, and the contribution of geophysical agents estimated at 1 to 3 percent.[44,45,46] Despite the fact that the contribution of environmental carcinogens to the cancer burden is not as well understood as some of the other major causes of cancer (e.g., diet and lifestyle), preventive measures can and should be initiated. Such measures are largely based on what is known at present, and include the reduction of exposure to hazardous chemicals in the workplace and the reduction of environmental pollution.[47]

Occupational risks for cancer are not often addressed because linking individual cancers to a specific occupational exposure is difficult due to the facts that cancer frequently takes decades to develop, cancer is a multifactorial disease, and exposures in the workplace are unclear and always changing. Of the

approximately 6,000 new cancer diagnoses made each year in Maine, 300 are due to an occupational exposure. Approximately 150 deaths per year are due to an occupation-related cancer.

Maine could do an assessment to determine what are the high-volume or high-risk industries and occupations in Maine. Exposure studies could be conducted on these industries and occupations. Interventions could be conducted to reduce exposures in these high-risk settings and evaluated to determine if they have been successful.

In addition to these efforts to reduce occupational exposures, two naturally occurring environmental carcinogens, radon and arsenic, are particularly worthy of increased preventive efforts because of the potential magnitude of their associated cancer burden for Maine residents.

Radon. Radon is a naturally occurring radioactive gas that enters homes primarily through soil gas and well water. The National Research Council (NRC) projected that between ten and fourteen percent of the 157,400 lung cancers that occurred nationally in 1995 resulted from residential radon exposure, making radon the second leading cause of lung cancer after cigarette smoking.[48] Most of these cancers attributed to radon exposure (87 percent) are expected to occur among Mainers who are currently smoking or did smoke at one time, a consequence of a synergistic effect of the two exposures occurring together. NRC has estimated that perhaps one-third of the radon-attributed lung cancer cases would be avoided if all homes had concentrations below the EPA action guideline of 4 picocuries of radon per liter of air (pCi/L).

One survey estimated that 30 percent of Maine residential homes have indoor air radon levels exceeding 4 pCi/L, and a study of 650 schools across the state found 32 percent had at least one classroom with a radon concentration above 4 pCi/L.[49] Radon contributed from domestic well water may also constitute a significant indoor-air radon problem in Maine.[50] Results of a survey of over 3,000 homes found one in six homes with domestic wells had high levels of radon in the water that could result in high indoor air levels of radon.[51]

Arsenic. Arsenic is a naturally occurring element found in ground water and surface water, as well as in many foods. Arsenic-containing pesticides were commonly used in many agricultural settings in Maine in the early to mid-1900s. The effect this has had on ground water is not well known. In its recent report on arsenic in drinking water, the NRC concluded that there is a causal relationship between chronic ingestion of inorganic arsenic and skin, bladder and lung cancer.[52] Current data indicate that somewhere between 2 and 14 percent of Maine households with domestic wells have water with arsenic levels exceeding 50 (g/L. Nationally, Maine has the third highest bladder cancer mortality rate for males and the sixth highest for females. Bladder cancer incidence is also elevated, though to a lesser extent. Bladder cancer is ranked sixth for causes of cancer mortality in Maine and ninth for cancer incidence.[53] The extent to which the elevated bladder cancer rates in Maine are attributable to arsenic is unknown, although this is to be assessed in an epidemiological study sponsored by the National Cancer Institute.

GOAL 5: Reduce the risk of cancer from carcinogens in Maine's environment.

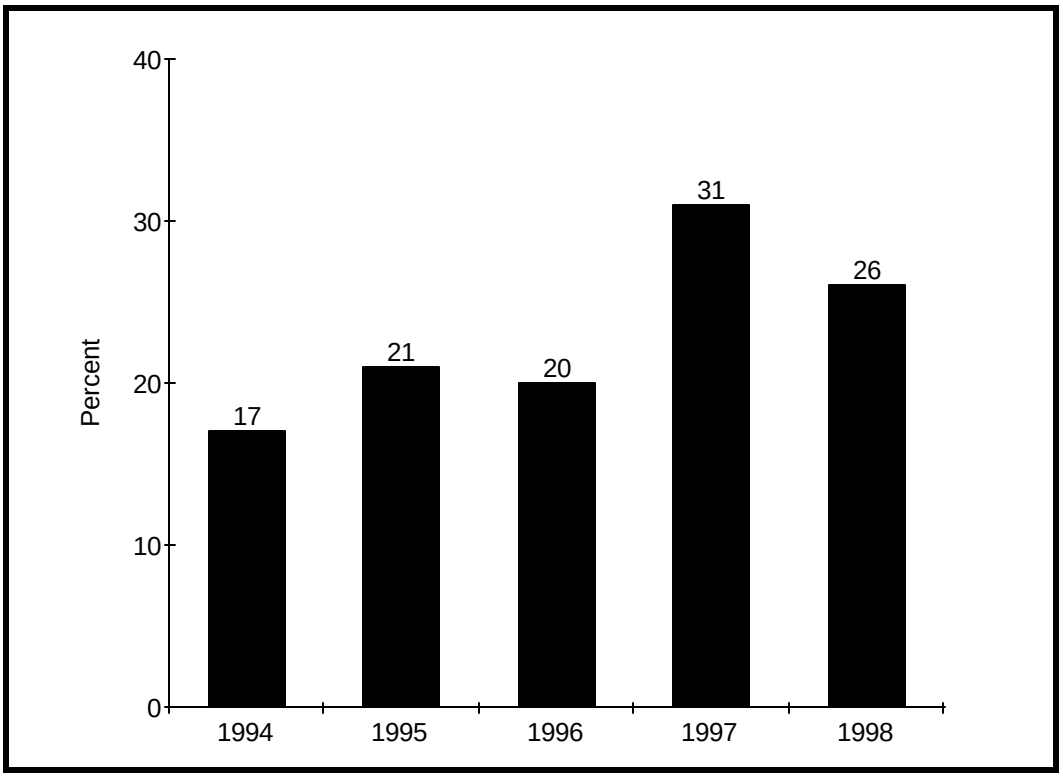
Objective 5.1

Decrease the proportion of homes and workplaces that have indoor air radon levels in excess of the U.S. EPA action guideline of 4 pCi/L.

Strategies

- Promote screening for indoor air levels of radon in Maine homes and workplaces.
- Continue to increase the proportion of homes known to have radon levels above 4 pCi/L that have taken corrective action to reduce levels to less than 4 pCi/L (Figure 17).

Figure 17 The Proportion of Homes Known to Have Radon Levels Above 4 pCi/L That Have Taken Corrective Action to Reduce Levels to Less Than 4 pCi/L



Source: Maine Bureau of Health, Division of Disease Control.

Objective 5.2

Decrease the proportion of homes and workplaces that have drinking water with arsenic levels above the World Health Organization guideline of 10 (g/L).

Strategies

- Increase the proportion of homes and workplaces that have tested their well water for arsenic by increasing public education efforts, persuading testing laboratories to add arsenic to standard water potability tests, and recommending that arsenic be listed as a test item on housing transaction purchase and sale agreements.
- Identify sources of financial assistance for purchase of water treatment systems or bottled water for households of limited income that have unsafe drinking water.
- Undertake research to confirm that point-of-use treatment systems (e.g., treatment at the kitchen sink) is sufficient to effectively reduce arsenic exposure from drinking water (i.e., confirm that bathing and other indirect water exposures are small).
- Strongly support the National Academy of Science's recommendation for a reduced national drinking water standard (MCL) for arsenic (current standard is 50 (g/L).
- Evaluate need for a State Arsenic Program, similar to current Radon Program and Lead Program.

Objective 5.3

Increase public awareness of and protection from carcinogens in the environment.

Strategies

- Increase awareness of fish advisories on Maine waters because of contamination with carcinogens such as dioxin, PCBs, DDT (1997 survey indicated 69 percent of Maine residents who had consumed fish from inland waters were aware of consumption advisories from newspaper articles, 24 percent said they had learned of the warnings from the fishing rule book).
- Support policies that reduce carcinogens in the environment.
- Support efforts to get Maine's Toxics Use Reduction / Pollution Prevention Program to consider chemical toxicity in assessing progress in toxics use reduction and in targeting resources to assist with pollution prevention efforts (rather than solely pounds released).

Early Detection

EARLY DETECTION WORK GROUP MEMBERS

*Evelyn Kieltyka**	*Family Planning Association of Maine/Maine Association of Nurse Practitioners*
*Linda Gray**	*American Cancer Society*
Terry Baker	American Cancer Society
Chriss Hayden	Portland Public Health Division
Stephanie Kimball	MaineGeneral Medical Center
Don Leaver	Central Maine Medical Center
Barbara Leonard	Bureau of Health
Dan Meyer	Maine Dartmouth Family Practice Residency
Iver Nielson	Redington-Fairview General Hospital
Laura Ronan	Medical Care Development
Mary Ann Weston	Bureau of Health, Public Health Nursing

***Work Group Chairs**

EARLY DETECTION

Early detection is carried out in the belief that the detection of disease in an early or asymptomatic stage will lead to appropriate treatment which, in turn, will lead to less disability and/or mortality from the disease.[54] The Early Detection Work Group has reviewed the data and literature on early detection of breast, cervical, colorectal, prostate, and skin cancer. The evidence suggests that there is some consensus on the effectiveness of screening for cervical cancer, breast cancer, and colorectal cancer. Screening guidelines have been developed by several national organizations for these cancers. (See Appendix D for a list of sources that have developed prevention and screening guidelines.)

Less attention has been paid to early detection of skin cancer. Recognition of changes in skin growth, however, is the best way to find early skin cancer. Adults should practice skin self-exam regularly and changes should be evaluated by a physician.[55]

There is no solid evidence that early detection of prostate cancer decreases mortality. Therefore, the Work Group does not recommend a public health early detection program for prostate cancer at this time. Rather, we propose further discussion and research on the issue to come to some consensus on what the public health message should be regarding the benefits and risks of early detection for prostate cancer.

The following is a brief discussion of and goals and objectives for early detection of breast, colorectal, cervical, prostate, and skin cancer. A section on the importance of monitoring advances in genetics and how this may affect early detection is also included.

BREAST CANCER

An estimated 182,800 new cases of female breast cancer are expected in the United States during 2000. After increasing about 4 percent per year in the 1980s, breast cancer incidence rates leveled off in the 1990s. In 2000, an estimated 40,800 breast cancer deaths will occur in U.S. women. Breast cancer is the second leading cause of cancer death among women. Mortality rates declined significantly for the first time during 1992-1996 for U.S. women. This decline is probably due to early detection and improved treatment.[56]

It is estimated that in 2000, 900 Maine women will be diagnosed with breast cancer and 200 will die from the disease.[57] Maine's incidence rate for breast cancer has been consistently lower than the United States rate (Figure 18), but the mortality rate has been essentially equal to the U.S. rate during this same time period (Figure 19). It appears that Maine experiences an excess of breast cancer mortality relative to what would be expected based on the incidence rate.

Figure 18 Comparison of Breast Cancer Incidence Rates for Maine and the United States

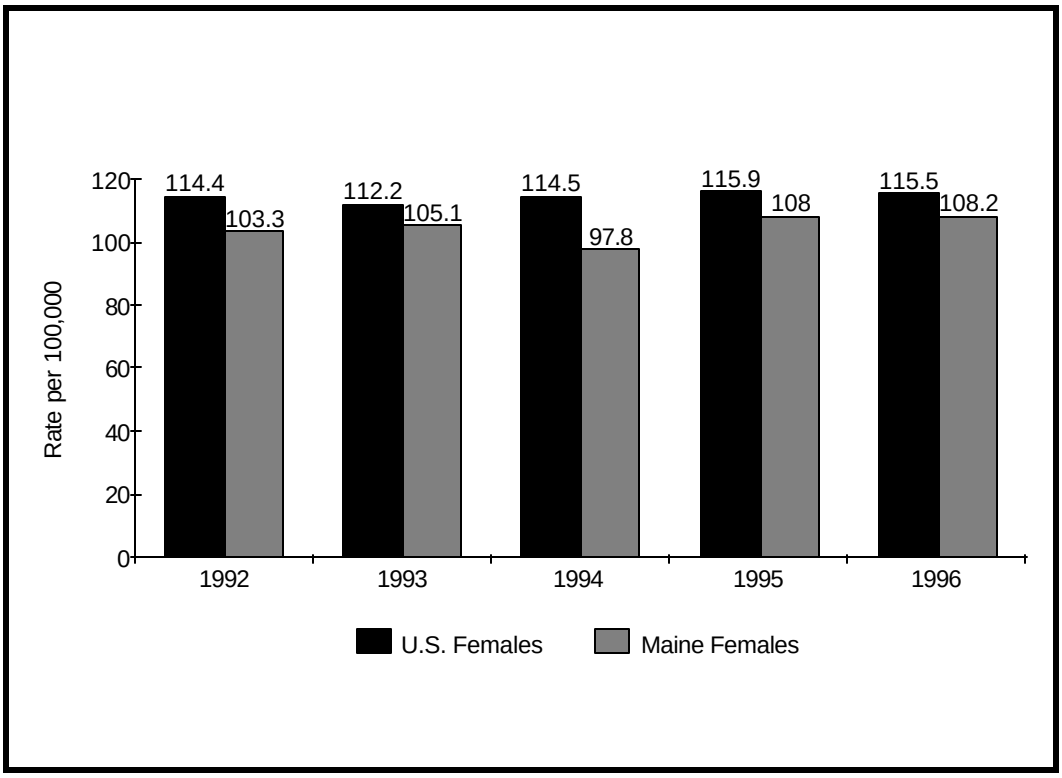
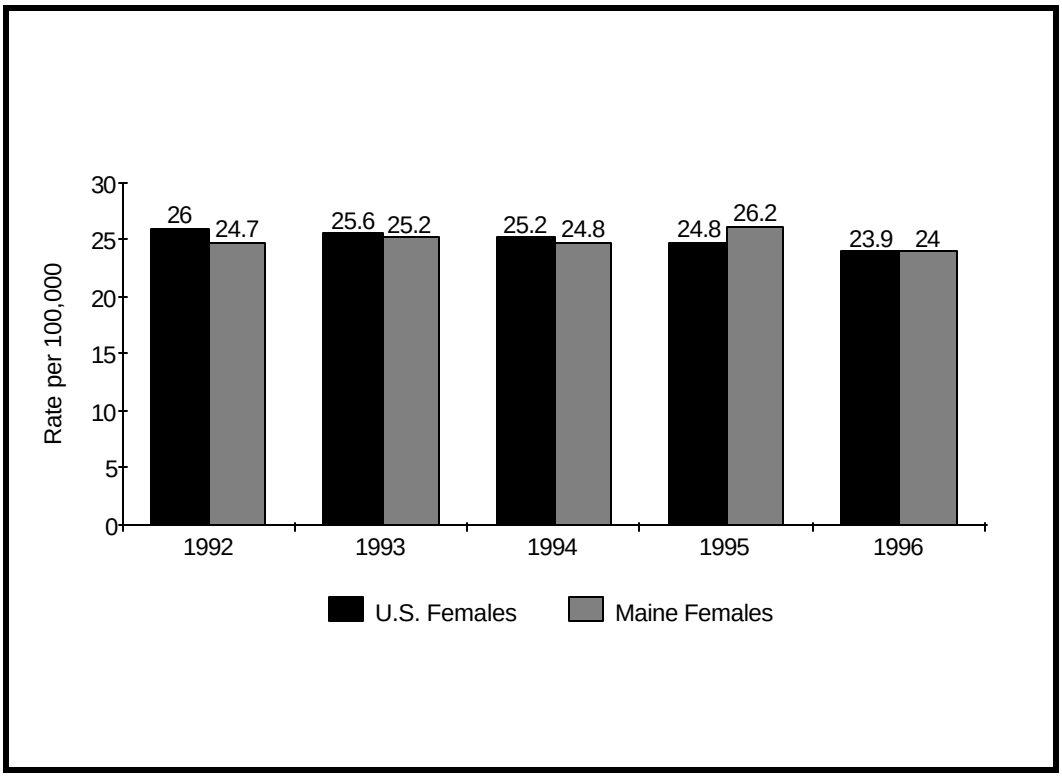


Figure 19 Comparison of Breast Cancer Mortality Rates for Maine and the United States



Many Maine women do not obtain cancer early detection services according to recommended screening guidelines. In 1998, 59 percent of Maine women age 50 and older received a mammogram and clinical breast exam in the past year, and 70.2 percent of women age 40-49 had a mammogram and clinical breast exam in the past two years.[58] The 1998 American Cancer Society guidelines recommend that women 40 and older have a mammogram and clinical breast exam annually. (See Appendix D for other sources that have developed cancer screening guidelines.)

GOAL 6: To promote, increase, and optimize the appropriate utilization of high-quality breast cancer screening and follow-up services.

Objective 6.1

Increase the proportion of Maine women aged 40-49 who have received both a mammogram and a clinical breast exam within the past two years to 80 percent by 2005. (Maine baseline: 70.2 percent have received both, BRFSS, 1998.)

Strategies

- Support ongoing implementation of Maine Breast and Cervical Health Program ([MBCHP], see Appendix A for a description of this program).
- Support implementation of the American Cancer Society (ACS) "Tell A Friend" program (see Appendix A for a description of this program).
- Seek state funds for payment of screening services for asymptomatic and low-risk women 40-49 in the MBCHP.
- Develop a model community-based intervention to promote breast cancer screening.

Objective 6.2

Increase the proportion of Maine women aged 50 and older who have received both a mammogram and a clinical breast exam within the preceding year to 70 percent by 2005. (Maine baseline: 59.5 percent have received both, BRFSS, 1998.)

Strategies

- Support ongoing implementation of Maine Breast and Cervical Health Program.
- Support implementation of ACS "Tell A Friend" program.
- Develop collaborative relationship with Northeast Healthcare Quality Foundation to provide outreach to Medicare beneficiaries.

Objective 6.3

Enhance the ability of health care providers to provide breast cancer screening tests and exams of the highest quality.

Strategies

- Provide periodic continuing education programs on mammography technique and clinical breast exam technique.
- Work with health professional training programs to teach students state-of-the-art techniques for breast cancer screening exams and tests.
- Support activities of the Maine Consortium for Office Systems Improvement (see Appendix A for a description of this program).

Objective 6.4

Increase the proportion of patients with abnormal breast cancer screening results who receive timely and appropriate follow-up.

Strategies

- Disseminate guidelines and protocols for screening and follow-up to health care providers through a variety of continuing education mechanisms.
- Support improvement of primary care office systems through implementation of reminder/recall systems, tracking systems, tickler systems, among others.

COLORECTAL CANCER

In 2000, an estimated 130,200 new cases of colorectal cancer are expected in the United States. Colorectal cancers are the third most common cancers in men and women. Incidence rates declined significantly during 1992-1996 (Figure 19). In 2000, an estimated 56,300 deaths will occur in the United States. Mortality rates have declined over the past 20 years. This is probably due to early detection and improved treatment.[59]

It is estimated that in 2000, 700 Mainers will be diagnosed with colorectal cancer and 300 will die from the disease.[60] Colorectal cancer is the second most common cancer in Maine. Although the incidence and mortality rates of colorectal cancer have decreased, these rates exceed U.S. rates (Figures 20 and 21).

Figure 20 Comparison of Colorectal Cancer Incidence Rates of Maine and the United States

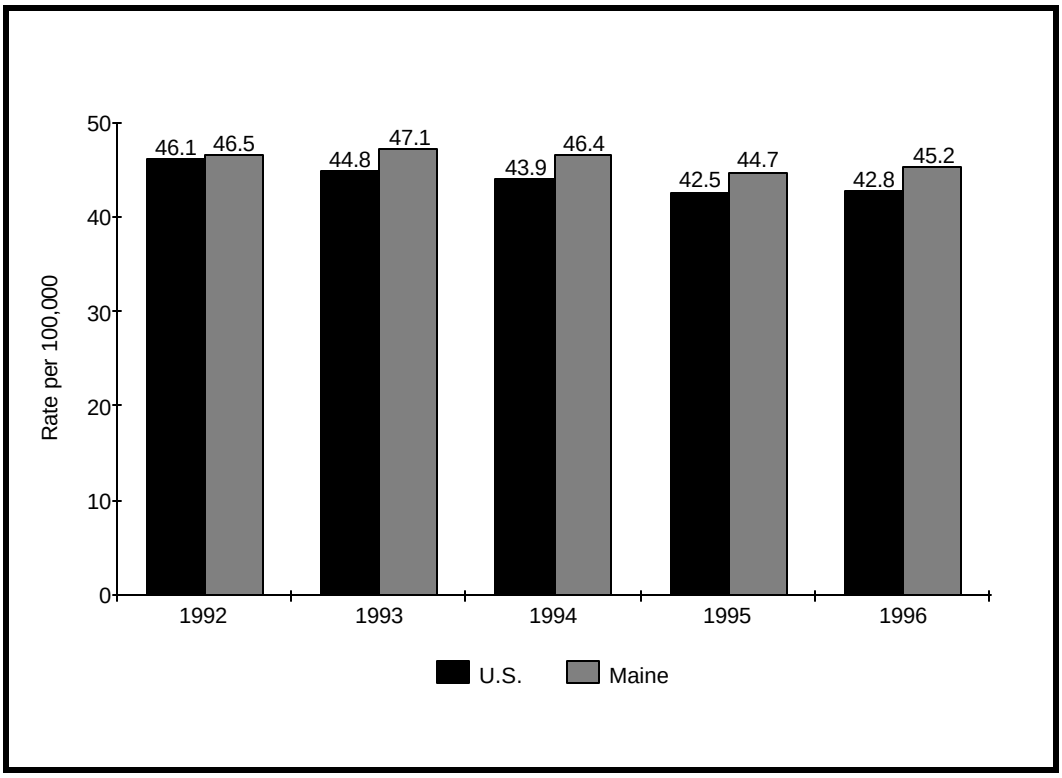
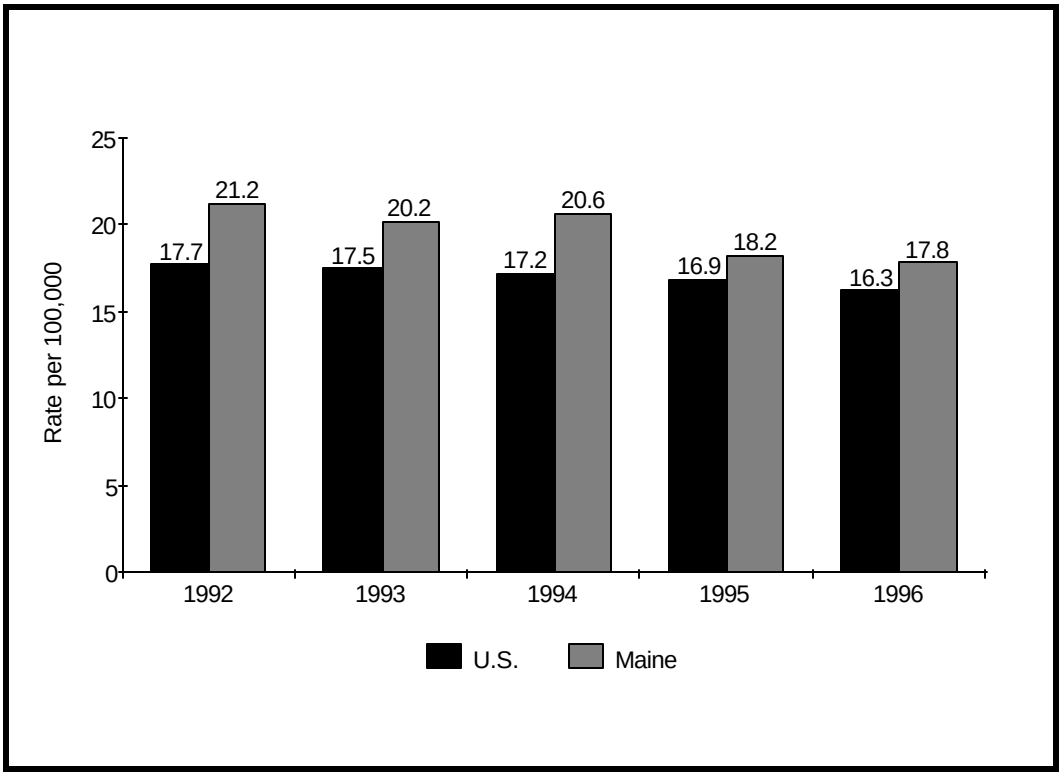
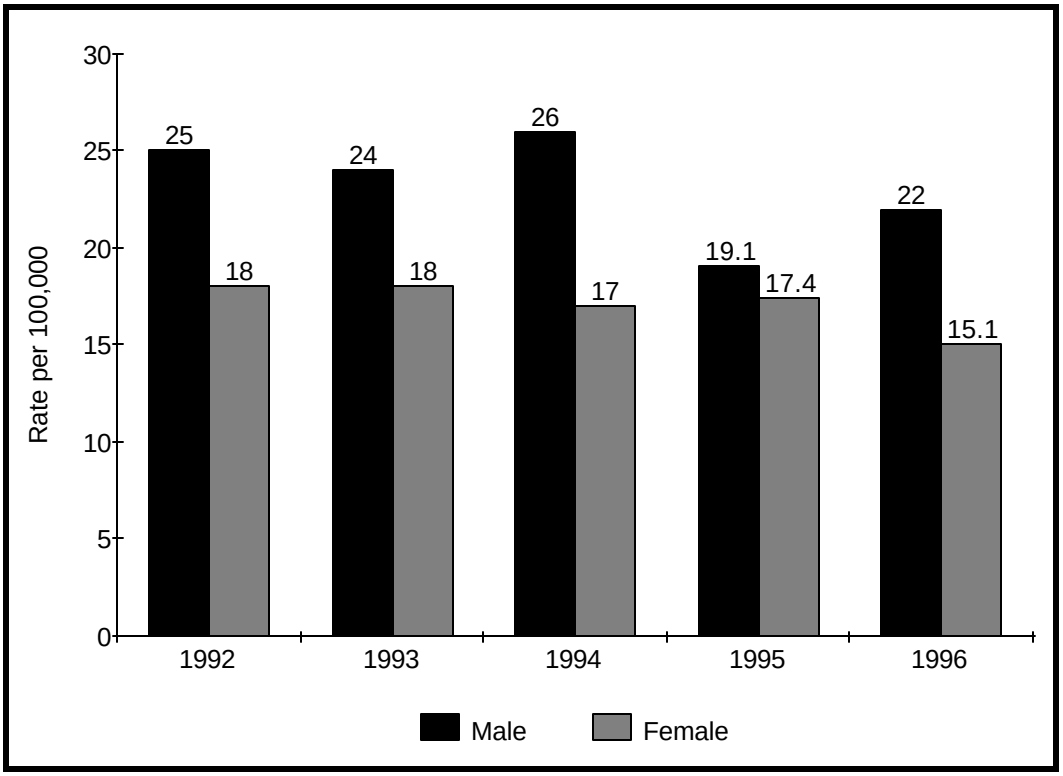


Figure 21 Comparison of Colorectal Cancer Mortality Rates of Maine and the United States



Maine colorectal cancer mortality rates are higher for males than females (Figure 22). Maine residents do not obtain colorectal cancer early detection services according to recommended screening guidelines. In 1999, 42.4 percent of Maine residents aged 50 and older reported they had ever had a sigmoidoscopy. Fewer men than women reported ever having had this screening test (39.7 percent vs. 44.5 percent). The American Cancer Society recommends that sigmoidoscopy or a fecal occult blood test be done beginning at age 50. (See Appendix D for other sources to contact for complete screening guidelines pertaining to colorectal cancer.)

Figure 22: Comparison of Maine Colorectal Cancer Mortality for Males and Females



GOAL 7: To promote, increase, and optimize the appropriate utilization of high-quality colorectal cancer screening and follow-up services.

Objective 7.1

Increase the proportion of people aged 50 and older who have received fecal occult blood testing (FOBT) within the preceding two years to 60 percent by 2005. (Maine baseline: 35.9 percent of all adults, 27.1 percent of men, and 43 percent of women age 50 and over had ever had a FOBT, BRFSS, 1999.)

Strategies

- Promote colorectal screening through public awareness campaigns.
- Develop professional education for primary care providers to support patient education and regular screening.

Objective 7.2

Increase the proportion of adults aged 50 and older who have received a flexible sigmoidoscopy every five years or colonscopy every ten years or double contrast barium enema every five to ten years to 45 percent by 2005. (Maine baseline: 42.4 percent of adults age 50 and older have ever received a proctoscopic or sigmoidoscopic exam, BRFSS, 1999.)

Strategies

- Inventory the number and location of providers who can perform the recommended services.
- Develop professional education to increase the number of providers who can perform recommended screening services in geographic areas with limited access.

Objective 7.3

Enhance the ability of health care providers to provide colorectal cancer screening tests and exams of the highest quality.

Strategies

- Provide periodic continuing education programs about colorectal screening guidelines and procedures.
- Work with health professional training programs to teach students state-of-the-art techniques for cancer screening exams and tests.
- Support activities of the Maine Consortium for Office Systems Improvement.

Objective 7.4

Ensure that patients with abnormal colorectal cancer screening results receive timely and appropriate follow-up.

Strategies

- Disseminate guidelines and protocols for screening and follow-up to health care providers through a variety of continuing education mechanisms.
- Support improvement of primary care office systems through implementation of reminder/recall systems, tracking systems, tickler systems, among others.

CERVICAL CANCER

In 2000, an estimated 12,800 new cases of cervical cancer are expected in the United States. Incidence rates have declined steadily over the past several decades. In 2000, an estimated 4,600 cervical cancer deaths will occur in the United States. U.S. mortality rates have sharply declined over the past several decades as Pap screening has become more prevalent. When detected early, cervical cancer and its precursors are among the most successfully treatable cancers.[61]

It is estimated that in 2000, 100 women will be diagnosed with cervical cancer and 29 will die from the disease.[62] Although cervical cancer incidence and mortality rates are decreasing in Maine and the United

States, Maine's incidence and mortality rates are higher than national rates (Figures 23 and 24). Cervical cancer remains a priority even though it is not a leading cause of mortality because it is nearly 100 percent preventable with early detection.

Figure 23 Comparison of Cervical Cancer Incidence Rates for Maine and the United States

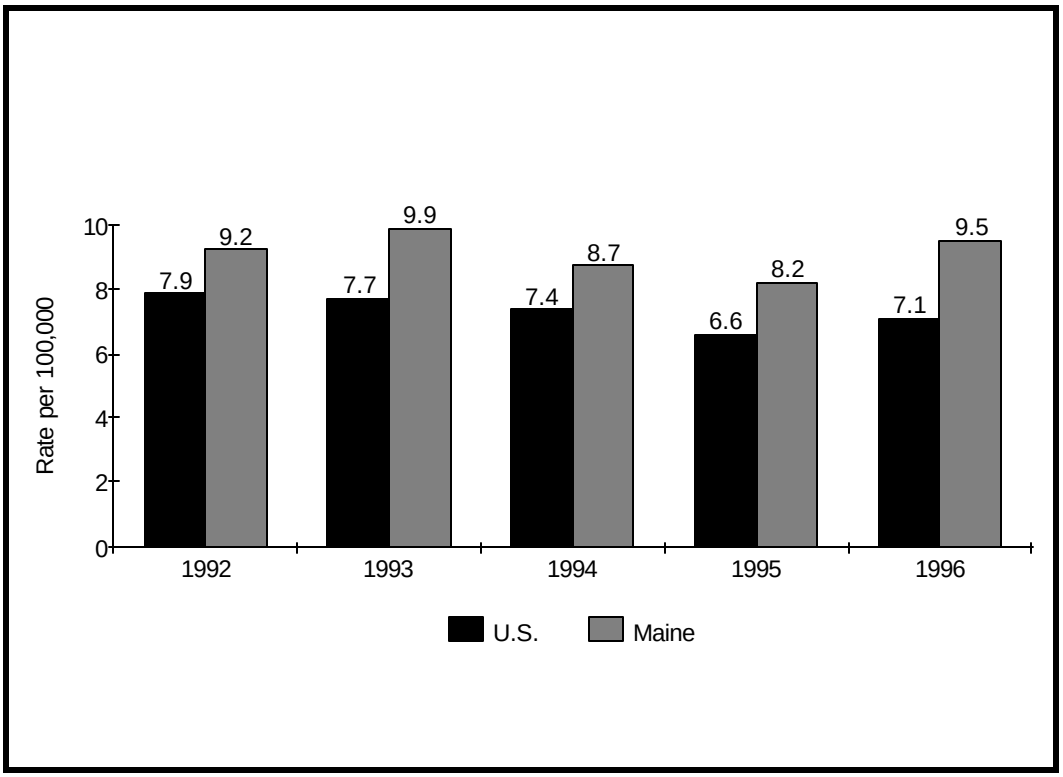
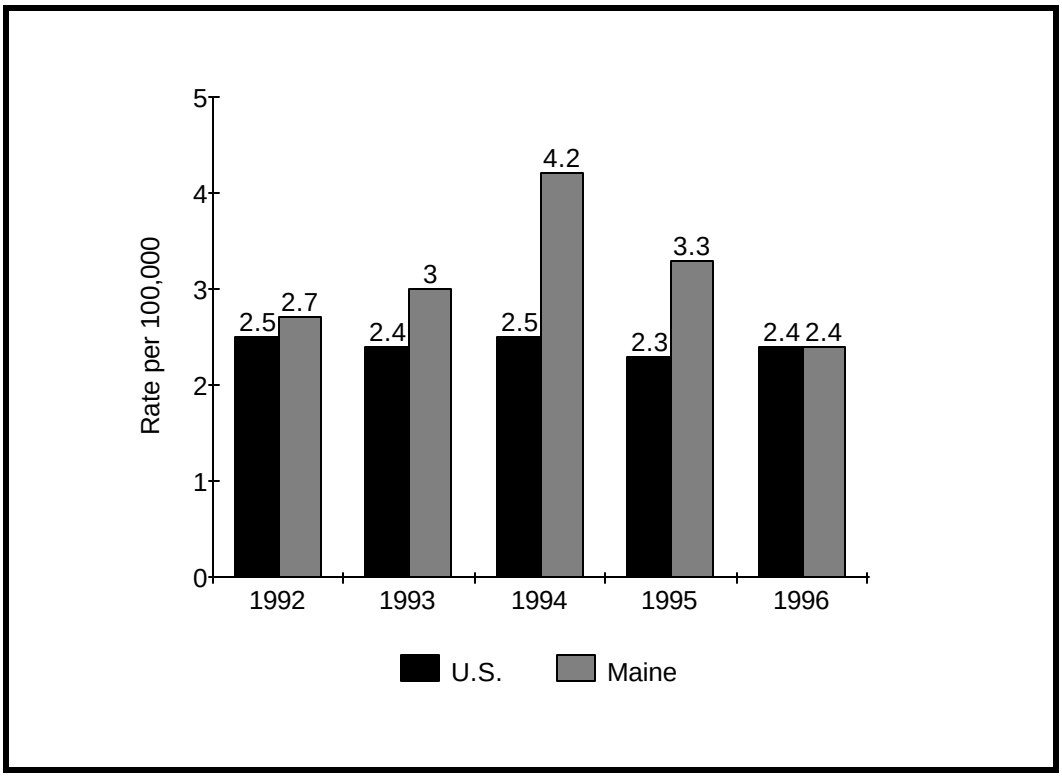


Figure 24 Comparison of Cervical Cancer Mortality Rates for Maine and the United States



Many Maine women do not obtain cervical cancer early detection services according to recommended screening guidelines. In 1998, 73.5 percent of women aged 18-44 had a Pap test in the past year, 84 percent of women aged 45-69 had a Pap test in the past three years, and 69.5 percent of women aged 70 and older had a Pap test in the past three years.[63] The 1998 American Cancer Society guidelines recommend that women who are or have been sexually active or who are 18 or older should have an annual Pap test. The test may be performed less frequently after three or more consecutive Pap tests with normal results. (See Appendix D for other sources of screening guidelines.)

GOAL 8: To promote, increase, and optimize the appropriate utilization of high-quality cervical cancer screening and follow-up services.

Objective 8.1

Increase the proportion of Maine women aged 18 and older with a uterine cervix who have ever received a Pap test to 98 percent by 2005. (Maine baseline: 95.3 percent of women aged 18 and older with a uterine cervix have ever received a Pap test, BRFSS, 1998.)

Strategies

- Support ongoing implementation of Maine Breast and Cervical Health Program (see Appendix A for a description of this program).
- Support ongoing funding of Title X (Family Planning) activities (see Appendix A for a description of this program).

Objective 8.2

Increase the proportion of Maine women aged 18 and older with a uterine cervix that received a Pap test within the proceeding 1 to 3 years to 90 percent, by 2005. (Maine baseline: 84.7 percent of women aged 18 and older with a uterine cervix have received a Pap test within the previous 3 years, BRFSS, 1998.)

Strategies

- Same as Objective 8.1.

Objective 8.3

Enhance the ability of health care providers to provide cervical cancer screening tests and exams of the highest quality.

Strategies

- Provide periodic continuing education programs about cervical cancer screening.
- Work with health professional training programs to teach students state-of-the-art techniques for cervical cancer screening exams and tests.
- Support activities of the Maine Consortium for Office Systems Improvement (see Appendix A for a description of this program).

Objective 8.4

Increase the proportion of patients with abnormal cervical cancer screening results who receive timely and appropriate follow-up.

Strategies

- Disseminate guidelines and protocols for screening and follow-up to health care providers though a variety of continuing education mechanisms.
- Support improvements of primary care office systems.

PROSTATE CANCER

Between 1989 and 1992, prostate cancer incidence rates increased dramatically in the United States, probably due to earlier diagnosis in men without any symptoms. In 2000, an estimated 31,900 deaths will occur in the United States. Mortality rates have declined significantly during 1992-1996.[64]

It is estimated that in 2000, 900 men will be diagnosed with prostate cancer and 200 will die from the disease.[65] Prostate cancer incidence rates in Maine are consistently lower than the United States rates. This is most likely due to under-reporting. Maine incidence rates, however, have not shown the decline in 1993 and 1994 that occurred in U.S. rates (Figure 25). Since 1988, Maine's prostate cancer mortality rates have been consistently higher than the United States rates (Figure 26). Prostate cancer is the second leading cause of cancer death for men in Maine.

Figure 25 Comparison of Prostate Cancer Incidence Rates for Maine and the United States

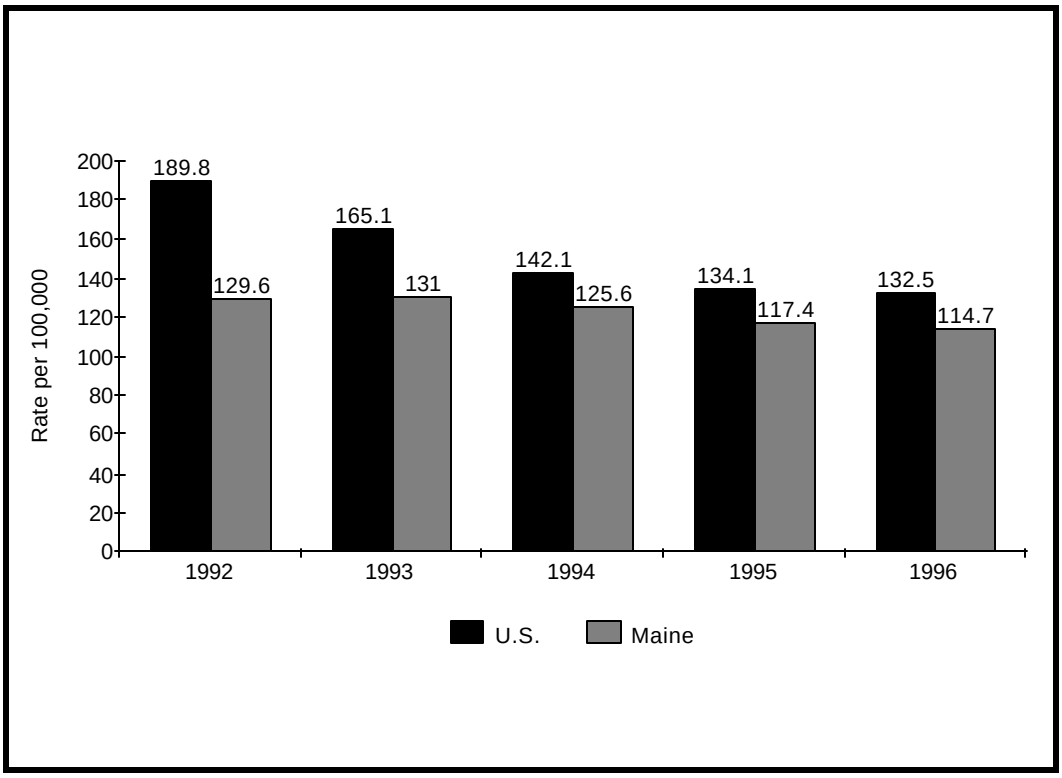
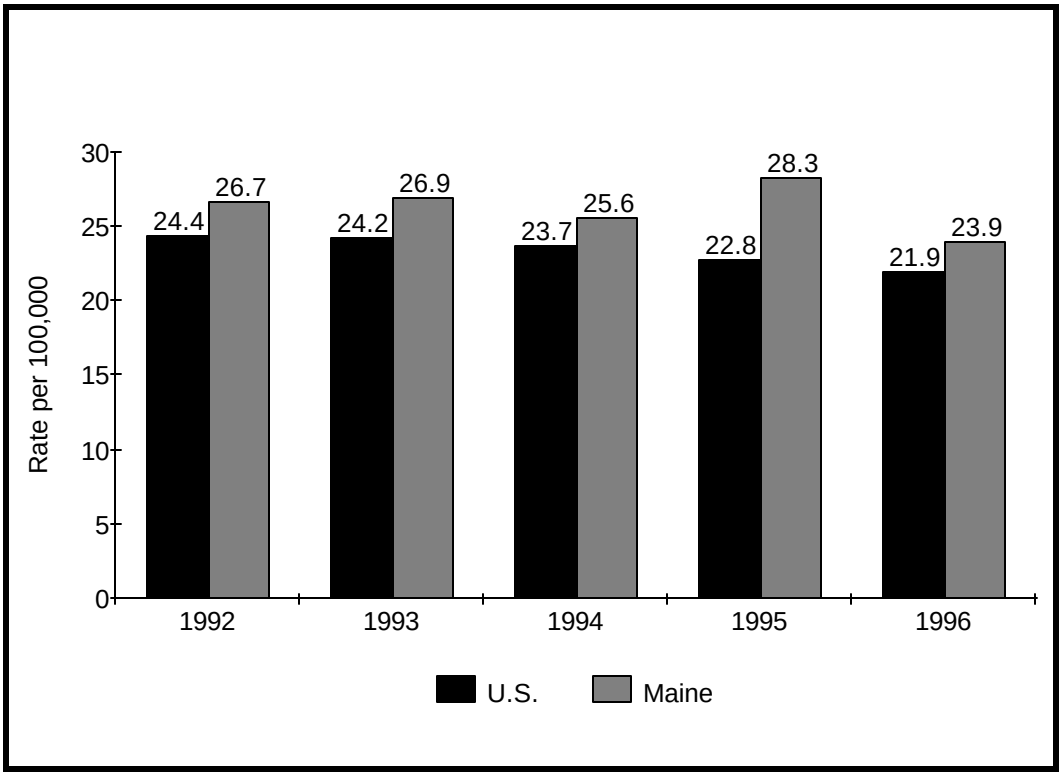


Figure 26 Comparison of Prostate Cancer Mortality Rates for Maine and the United States



Whether to recommend screening for prostate cancer among asymptomatic men is a difficult public health issue. There is currently no consensus among major medical and health organizations in the United States about recommendations for screening.

GOAL 9: To arrive at a consensus on what the public health message should be regarding prostate cancer screening and the benefits and risks of early detection.

Objective 9.1

Develop a prostate cancer screening message for Maine and develop strategies for incorporating new information.

Strategies

- Convene a diverse working group to review current literature and develop a message. When a consensus message is obtained, pursue public, clinician, and patient education objectives.
- Investigate the possibility of a coalition or advocacy group for prostate cancer.

SKIN CANCER

In 2000, an estimated 1.3 million new cases of highly curable basal cell or squamous cell cancers are expected in the United States. Melanoma is the most serious form of skin cancer and is expected to be diagnosed in about 47,700 people in 2000. Since the early 1970s, the incidence rate of melanoma has increased significantly (on average 4 percent per year). Melanoma is the most rapidly increasing form of cancer in the United States. In 2000, an estimated 9,600 skin cancer deaths will occur in the United States, 7,700 from melanoma and 1,900 from other skin cancers.[66]

It is estimated that in 2000, 200 Mainers will be diagnosed with melanoma and approximately 30 will die from this most serious form of skin cancer.[67] It appears that incidence of melanoma is increasing in Maine (Figure 27). When diagnosed at an early stage, it can usually be cured. Melanoma mortality rates in Maine are higher than would be expected based on the incidence rate (Figure 28).

Figure 27 Comparison of Melanoma Cancer Incidence Rates for Maine and the United States

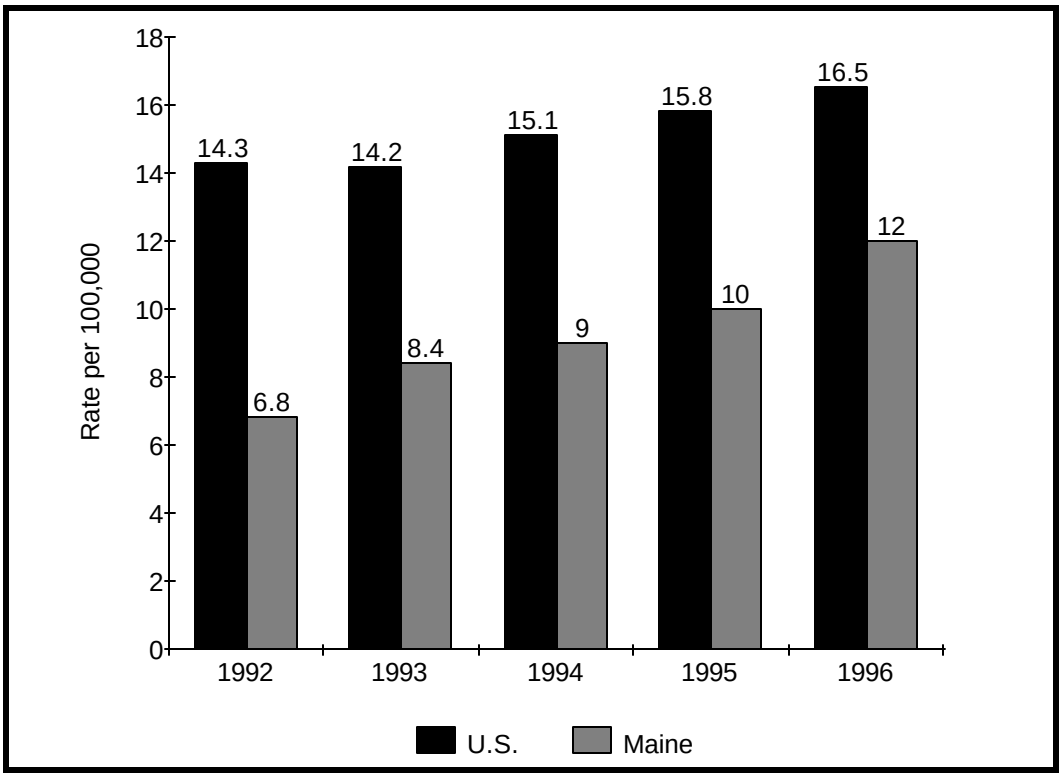
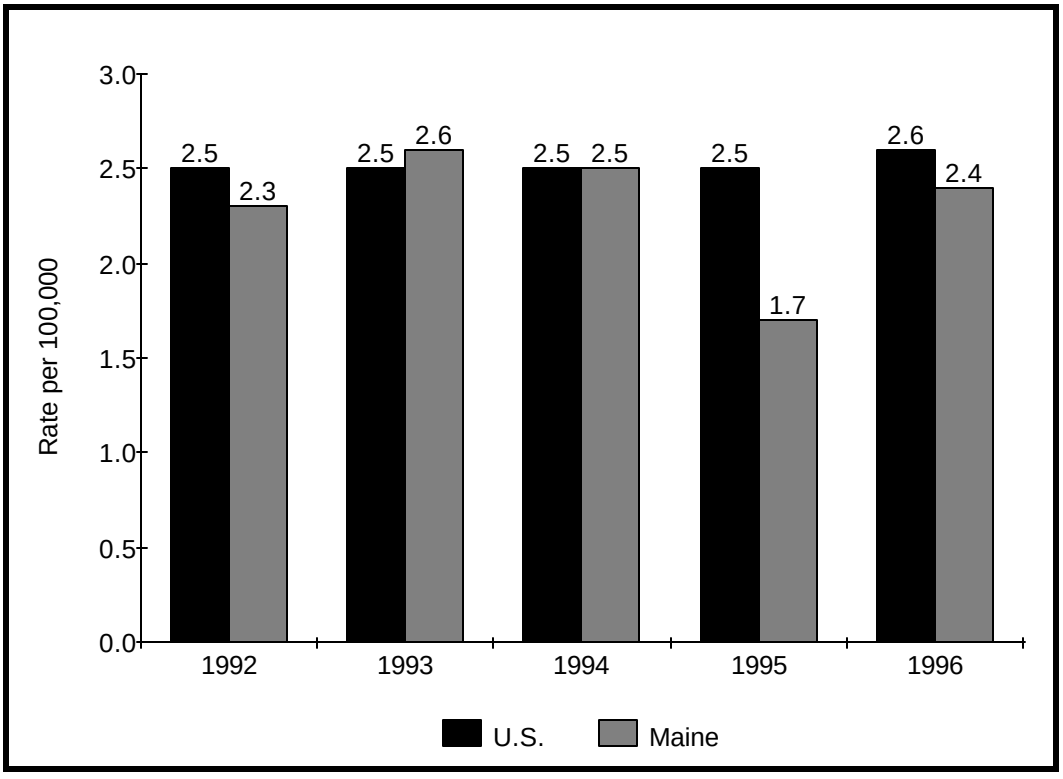


Figure 28 Comparison of Melanoma Cancer Mortality Rates for Maine and the United States



GOAL 10: To promote, increase, and optimize early skin cancer screening and follow-up services.

Objective 10.1

Promote public awareness of the risk factors and early signs of malignant melanoma.

Strategies

- Develop public service announcements and distribute American Cancer Society educational materials.
- Promote worksite education through employee wellness programs.

Objective 10.2

Promote awareness of the need for total body examination and enhance the ability of health care providers to provide high-quality skin cancer screening tests.

Strategies

- Provide periodic continuing education programs on skin screening.
- Work with health professional training programs to teach students state-of-the-art techniques for cancer screening exams and tests.
- Work with third-party payors to assure adequate reimbursement for skin cancer screening.
- Assist providers in the development of efficient office procedures to provide patient screening.

Objective 10.3

Assure that all patients with abnormal skin cancer screening results receive timely and appropriate follow-up.

Strategies

- Disseminate guidelines and protocols for screening and follow-up to health care providers through a variety of continuing education mechanisms.
- Support improvement of primary care office systems through implementation of reminder/recall systems, tracking systems, tickler systems, among others.

GENETICS

Genetic factors clearly play a role in the development of cancer. Genetic mutations may be inherited or may be caused by exposure to specific agents. There is increasing information that some people are predisposed to cancers because of inherited genetic syndromes. This raises a variety of questions, including the appropriateness of screening for inherited genetic syndromes, the need for informed consent for genetic screening, and the desire for protection of genetic information (particularly in the contexts of health insurance). These and similar issues will need to be monitored in the future.

GOAL 11: Improve public and professional awareness about developments in cancer genetics.

Objective 11.1

Promote public awareness of cancer risks and the need for proper counseling prior to participating in genetic studies or screening.

Strategy

- Monitor evaluation of National Comprehensive Cancer Network Guidelines vis-à-vis screening.

Objective 11.2

Increase public awareness of the availability of genetic services.

Strategies

- Monitor evaluation of National Comprehensive Cancer Network Guidelines vis-à-vis screening.
- Create public educational materials on available genetic services, what the public can expect to receive with genetic services, and what are "appropriate" uses of genetic service resources.

Objective 11.3

Promote awareness among health professionals about developments in cancer genetics, and social, legal, and ethical issues.

Strategies

- Monitor evaluation of National Comprehensive Cancer Network Guidelines vis-à-vis screening.
- Educate health professionals about what genetic services are available in Maine and how to access them.

TREATMENT

TREATMENT WORK GROUP MEMBERS

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***Chair**

TREATMENT

The goal of cancer treatment is to cure the person with cancer or control the progression of the disease while maintaining the highest quality of life possible. Treatment for many cancers has improved over the past ten years. New chemotherapy drugs, better surgical techniques, improved radiation therapy, biological therapy, and increasing use of multi-modality therapy have combined to increase survival rates.[68]

In some instances drug treatments can be used to prevent the development of cancer in high-risk people. Chemoprevention refers to the use of drugs or other agents to suppress or prevent the development of cancer. Research in chemoprevention has expanded greatly in the 1990s to include a number of large clinical studies. Of particular public health interest are the studies related to cancers for which effective early detection exists: breast, colorectal, and skin cancer.[69]

In addition to using mainstream cancer treatment, some people with cancer are using complementary and alternative medicine (CAM). CAM includes a broad range of healing philosophies, approaches, and therapies that are usually used to prevent illness, reduce stress, prevent or reduce side effects and symptoms, or control or cure disease. Some commonly used CAM modalities include mind/body control interventions such as visualization or relaxation, acupressure and massage, homeopathy, vitamins or herbal products, and acupuncture (NCI, Cancer Net). One large study found that approximately 9 percent of cancer patients in the U.S. have used CAM (Lerner and Kennedy, 1992 in NCI, CancerNet). Limited research has been conducted to determine the safety and effectiveness of CAM.

Cancer is a complex, chronic disease that often requires or uses exhaustive health care services and technologies. To reduce the burden of cancer in Maine, treatment must be available, affordable, accessible, and state-of-the-art. One of the goals of the Consortium and the Treatment Work Group is to determine the extent to which cancer patients have access to appropriate care, to determine whether any gaps in care exist, and to develop ways to reduce or eliminate any gaps that are identified. The Treatment Work Group identified access to and quality of treatment information and care as priority areas on which to focus for the next five years.

Access to Treatment Information and High-Quality Services. In order to receive cancer treatment, patients must be aware of the need for and availability of treatment services. Education is an important component of treatment. Knowledge about treatment services can empower patients and their families when decisions must be made about cancer treatment options, support services, among other aspects of care.

In addition to knowledge of available services, people must also have both geographic and financial access to treatment services. While many believe that there is a lack of available and accessible cancer treatment in Maine, it is unknown what, if any, gaps exist in the cancer treatment delivery system. There is a need to document what services are being provided geographically, as well as to determine service patterns. It is also necessary to look into whether finances are influencing treatment choices, e.g., choosing a more invasive option that is viewed as being less costly in the long run, such as a mastectomy rather than a long course of chemo- and radiation therapy.

Access to treatment services is not enough; services must also be of high quality. Hospitals approved by the American College of Surgeons (ACoS) Commission on Cancer ensure quality cancer care through

the availability of state-of-the-art technology, access to multidisciplinary consultation and treatment, and ongoing quality assessment that monitors treatment effectiveness and outcomes. Currently, there are 38 hospitals in Maine that diagnose or treat cancer patients and report these cancers to the Maine Cancer Registry. Of these, 10 (26 percent, 1993-1994) have received ACoS approval. The proportion of Maine hospitals with ACoS approval is similar to that of the United States (25 percent, 1999); however, the proportion of cancer cases treated in ACoS-approved hospitals is lower in Maine (72 percent, 1993-1994) than in the United States (80 percent, 1992).

In addition to access to ACoS-approved cancer treatment hospitals, access to clinical trials is considered another hallmark of quality care. Access to clinical trials requires that physicians and patients be aware of the availability and appropriateness of specific trials and the ability of physicians to place patients in trials. Access to clinical trials may not necessarily be guaranteed by insurance coverage. Currently, Maine has no data on the number of patients eligible to participate in clinical trials. Participation in clinical trials offers patients access to state-of-the-art interventions.

And lastly, there are several nationally recognized guidelines for cancer treatment. Utilization of these guidelines leads to improved quality of care as they provide guidance to providers and standardization of care. Consistent use of nationally approved guidelines, such as those published by National Comprehensive Cancer Network, will lead to improvement in the quality of cancer care throughout Maine.

GOAL 12: To assure that all Maine residents have financial and geographic access to high-quality cancer treatment information and services, including clinical trials, that comply with nationally recognized guidelines.

Objective 12.1

Develop a public awareness campaign to promote and enhance patient and family education regarding knowledge of diagnosed cancer, awareness of treatment options and resources, including clinical trials and complementary therapy, and support services through enhanced communication between the patient, family, and the oncology team.

Strategies

- Develop a website on available cancer treatment resources in Maine.
- Encourage use of the NCI and ACS websites and 800 numbers.
- Provide professional education through grand rounds on communication techniques.
- Develop a system of cancer survivors and advocates for patient and family support and advocacy.

Objective 12.2

Increase access to cancer treatment options, regardless of geography or financial resources for all Maine residents.

Strategies

- Identify treatment options and resources throughout the state.
- Identify gaps in treatment options and resources and develop strategies to adjust options.
- Identify location of cancer treatment facilities (including radiation), cancer cases, and health services areas for all regions of the state.
- Identify methods of payment and support resources available during cancer treatment (lodging, transportation, child care, among others).

Objective 12.3

Increase the number of hospitals in Maine that participate in American College of Surgeons Commission on Cancer Programs. (Maine baseline: 26 percent were ACoS-approved, 1993-1994.)

Strategies

- Survey ACoS- and non ACoS-approved hospitals to assess current linkages.
- Determine feasibility of creating affiliate accreditation programs between ACoS-and non ACoS-approved hospitals.
- Promote the benefits of ACoS approval to hospital administrators.
- Survey non-ACoS hospitals to determine interest in approval.
- Evaluate each hospital to determine the appropriate ACoS cancer program category it could become.
- Survey ACoS-approved hospitals about interest in developing affiliate programs.

Objective 12.4

Increase patient participation in clinical trials.

Strategies

- Increase public awareness of clinical trials through hospitals, public awareness campaigns, among other means.
- Provide professional education to providers to increase awareness of availability of and participation in clinical trials.
- Assess impact of insurance coverage in Maine on access to clinical trials.

Objective 12.5

Increase the use of the National Comprehensive Cancer Network guidelines or other nationally recognized organizations for cancer care among cancer treatment providers in Maine.

Strategies

- Work with organizations in Maine to promote the use of guidelines with providers (for example, Maine Medical Association, Maine Chapter of the American College of Surgeons, Maine State Nurses Association, among others.).
- Develop and implement professional education for providers on the use of guidelines.

The Maine Consortium for Comprehensive Cancer Control will monitor research regarding the use of complementary and alternative medicine in cancer treatment and will make program decisions based on the best available science.

Rehabiltation and Survivorship

REHABILITATION AND SURVIVORSHIP WORK GROUP MEMBERS

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***Chair**

REHABILITATION AND SURVIVORSHIP

Today, more than 50 percent of people diagnosed with cancer survive their disease for five years or longer.[70] As a result, issues pertaining to cancer patient quality of life, rehabilitation, and preservation of function have become increasingly important.

The National Coalition for Cancer Survivorship defines survivorship as beginning at diagnosis and continuing through the remainder of life. During the period of survivorship, individuals may be faced with physical, emotional, social, and vocational challenges. Counseling, support groups, and techniques for symptom management all may influence the quality of life of the cancer survivor.

The Rehabilitation and Survivorship Work Group identified access to quality rehabilitation and survivorship services and increasing the utilization of these services as priority issues for Maine for the next five years.

GOAL 13: To increase statewide coordination and provision of high-quality rehabilitation and survivorship services and increase utilization of these services by all Maine residents.

Objective 13.1

Determine how rehabilitation and survivorship services in Maine affect the quality of life for cancer survivors and their families.

Strategies

- Identify what rehabilitation and survivorship services are available.
- Complete quality-of-life and service impact assessments.

Objective 13.2

Increase statewide coordination and provision of quality rehabilitation and survivorship services.

Strategies

- Identify what rehabilitation and survivorship services are available.
- Develop a comprehensive, statewide website, which includes information on rehabilitation and survivorship along with prevention, early detection, treatment, and palliation services.
- Promote access to and utilization of the website among providers.
- Work with existing organizations and providers to promote knowledge of available services among each other.

Objective 13.3

Identify "best practices" for rehabilitation and survivorship services.

Strategies

- Conduct review of nursing, social work, and other related literature to determine if models exist.
- Consult with the National Coalition of Cancer Survivorship, ACS, ACoS and NCI regarding standards/guidelines/models for both service and delivery.
- Determine if national standards for cancer rehabilitation and survivorship services exist.
- Evaluate the extent to which Maine service provision meets recommended standards.

Objective 13.4

Encourage adoption of "best practices" of rehabilitation and survivorship services among providers.

Strategies

- Develop a strategy for the promotion of "best practices."
- Conduct professional education for providers on "best practices."
- Identify and disseminate nationally recognized tools and performance scales to assess quality of services.
- Provide professional education to providers on rehabilitation and survivorship services.
- Develop a statewide annual cancer conference in which rehabilitation and survivorship services are discussed.

Objective 13.5

Increase utilization of rehabilitation and survivorship services.

Strategies

- Assess the extent to which rehabilitation and survivorship services are offered and utilized and what the barriers are to service referral and utilization.
- Determine if services are adequately offered and utilized in comparison to the number of patients diagnosed with cancer.
- Examine Americans with Disabilities Act and worker's compensation cases to determine if appropriate services are offered/utilized.
- Develop strategies to address identified barriers.
- Promote awareness of rehabilitation and survivorship services among Mainers through website and print material development and use or distribution.
- Advocate for reimbursement of rehabilitation/survivorship services by third party.
- Identify what services are reimbursed and by whom.
- Work with third-party payors and/or legislature on reimbursement issues.

PALLIATIVE AND HOSPICE CARE

PALLIATIVE AND HOSPICE CARE WORK GROUP MEMBERS

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Margaret Parsons	Maine Bureau of Health
Sharron Sieleman	Central Maine Medical Center
Kathy Stuchiner	Maine Hospital Association
Donna Thompson	Central Maine Medical Center

***Chair**

PALLIATIVE AND HOSPICE CARE

Pain control is a significant problem for many cancer patients. Even though the pain associated with cancer can be managed effectively in most patients, cancer pain is often under treated. The consequences of ineffective management of cancer pain include unnecessary suffering, disability, and reduced quality of life. Reasons for ineffective management of cancer pain include lack of knowledge on the part of patients and health providers, negative attitudes toward the use of drugs, fear of drug addiction, restrictive drug regulations, concerns about cost, and reimbursement barriers.

The Palliative and Hospice Care Work Group identified health care provider training in palliative care, addressing cultural barriers to palliative and Hospice care, and availability, access to and quality of palliative and hospice care services as priority issues for Maine for the next five years.

Availability and Access (Financial, Geographic, etc.) to High-Quality Palliative and Hospice Care. Some health care providers are inadequately trained for comprehensive palliative or hospice care and, therefore, do not know how to talk with patients and family regarding hospice issues. In addition, there is insufficient availability, accessibility, and integration of hospice and palliative care services in our health care system. There are many people who could be receiving palliative and hospice care but do not due to insurance restrictions, financial constraints, lack of available services, geography, inadequate public transportation, and untimely referrals. There is no hospice Medicaid benefit, and the Medicare benefit is inadequate. These programs currently require significant private donations to provide quality care.

Cultural Barriers. The Public is often culturally unprepared, unaware of, and reluctant to seek Hospice care. In American culture, there is a recognizable lack of acceptance of death. Western culture often tries to deny death as a natural process. This culture may create an atmosphere where some people are unprepared for their own death or the death of a loved one. They may also be unaware of the services and support that are available or they may be reluctant to seek out those services and support.

GOAL 14: Assure that palliative care and hospice services are integrated into the health care system, that all Maine residents have financial and geographic access to high-quality palliative and hospice care, and that Mainers are more aware of, better prepared for, and more willing to seek hospice care.

Objective 14.1

Increase the proportion of health care providers caring for cancer patients who have additional certifications in hospice and palliative care.

Strategies

- Gather baseline data of current training levels.
- Support education curriculum and conferences covering palliative and Hospice care.
- Develop undergraduate curriculum for health care students.
- Develop continuing education classes for health care professionals.
- Palliative and Hospice care education programs will address cultural and ethnic diversity issues.

- Require certain number of hours (by board of licensure) in palliative care.
- Develop certificates in palliative and Hospice care for each specialty (e.g., physicians, nurses, Certified Registered Nurses in Hospice, hospice management).

Objective 14.2

Develop mentoring programs in palliative care for health care providers.

Strategies

- Assess existing mentoring programs.
- Develop mentoring programs for Hospice care.
- Identify Interdisciplinary Team members who have expertise in Palliative and Hospice Care.
- Recruit mentors for program.

Objective 14.3

Integrate Hospice and Palliative Care Services into the health care system and make these services available and accessible to all Mainers.

Strategies

- Partner with Maine provider organizations (e.g., Maine Hospital Association, Home Care Alliance of Maine, among others) to promote the development of strategic plans that reflect an interdisciplinary approach to palliative care. These plans would include: identification of patients; approaches to pain and symptom management; psychosocial concerns; Hospice issues; reimbursement coverage; policies and procedures; and standards.
- Develop resident palliative care and hospice facilities.
- Educate health care professionals about the technical amendment to the Medicare Hospice • Benefit that states that discharge planners must tell appropriate patients and families about hospice services in their communities.

Objective 14.4

Increase reimbursement for palliative care services in all settings, including home health care or hospice.

Strategies

- Work with the Maine Health Maintenance Organization Council regarding appropriate and accessible benefits.
- Publish annual comparison report on palliative and hospice care benefits.
- Aggressively pursue a comprehensive Medicaid hospice benefit for the State of Maine.
- Develop an education program for third-party payors regarding compassionate and cost effective Hospice care.
- Encourage the development of hospice programs within long-term care settings.

- Continue to advocate for (1) improvements in Medicare hospice reimbursement; (2) changes to Medicare hospice policies to improve access; and (3) work with the Medicare intermediaries to insure reasonable policy interpretation.

Objective 14.5

Include Palliative Care indicators in Quality Improvement Programs in appropriate health care institutions and agencies in Maine.

Strategies

- Collect baseline data to begin benchmarking progress in Maine.
- Evaluate data from Joint Commission on Accreditation surveys beginning in 2001.

Objective 14.6

Increase public awareness of hospice to at least 55 percent by 2005.

Strategies (Attention to cultural and ethnic issues will apply to each strategy.)

- Develop adult education programs.
- Publish resource guide – paper and electronic.
- Create speakers bureau.
- Develop discussion groups on the Internet.
- Develop public service announcements to increase awareness of hospice.
- Develop a weekly newspaper column – a "Dear Abby" for cancer care, Hospice care, and palliative care (Target Audiences are municipal offices, referral agencies, religious communities, labor unions, civic organizations, schools, consumers of health care and their support network, employers, medical office support staff, other social/community groups).
- Produce special media programs to increase awareness of hospice.

Objective 14.7

Better prepare Mainers to access Hospice care.

Strategies

- Same as Objective 14.6.

Objective 14.8

Increase hospice Medicare referrals to at least the national average by 2005.

Strategies

- Same as Objective 14.6.

Data and Cancer Surveillance

DATA AND CANCER SURVEILLANCE

The first step in this comprehensive cancer control planning process was to collect and analyze all relevant cancer data to provide a solid foundation for developing goals and objectives that focused on areas of greatest need and had the greatest likelihood of succeeding. During this process, it became apparent that there were gaps in available data and that additional sources of data needed to be developed to assist with future planning efforts.

More specifically, cancer surveillance data are crucial for identifying areas where greater prevention efforts are needed, for identifying potential causes of cancer, and for monitoring progress toward reducing cancer mortality. The National Cancer Institute's Surveillance, Epidemiology and End Results program collects cancer incidence data from regions of the United States and are useful for tracking trends in cancer incidence. United States mortality rates are based on counts of cancer deaths compiled by the National Center for Health Statistics.

The Maine Cancer Registry program has been responsible for collecting cancer incidence data for Maine since 1983. More resources need to be made available to report complete and accurate staging of all cancers in Maine according to standards of staging cancer, such as, the ACoS guidelines.

GOAL 15: Improve data collection and cancer surveillance in Maine.

Objective 15.1

Increase the extent to which cancer planning and programming decisions are made on the basis of sound evidence by health professionals and the Consortium (including feedback from routine evaluation of existing and future programs and services).

Strategies

- Identify data gaps and needs.
- Develop plan to address identified data gaps.
- New data used to assess, strategize, and prioritize future activities.

Objective 15.2

Increase the proportion of cancers reported with summary staging information to 90 percent by 2005. (Maine baseline: 88 percent have summary stage in 1995/1996.)

Strategy

- Provide targeted training at meetings of Cancer Registrars of Maine.

Objective 15.3

Increase the proportion of cancers reported by ACoS-approved hospitals with American Joint Commission on Cancer (AJCC) stage to 95 percent by 2005. (Maine baseline: 92 percent, 1994.)

Strategies

- Provide targeted training at meetings of Cancer Registrars of Maine.
- Provide hospital-specific feedback on proportion of cancers correctly reported with summary stage.

Objective 15.4

Enhance the capacity of the Maine Cancer Registry.

Strategy

- Convene workgroup to discuss the capacity needs and make recommendations.

Objective 15.5

The Maine Cancer Registry will have high-quality and complete data for first course of treatment for all cancer cases.

Strategies

- Provide targeted training at meetings of Cancer Registrars of Maine.
- Improve access of smaller hospitals to trained Certified Tumor Registrars.

Objective 15.6

The Maine Cancer Registry will provide summary data to cancer treatment providers.

Strategies

- Provide targeted training at meetings of Cancer Registrars of Maine.
- Improve access of smaller hospitals to trained Certified Tumor Registrars.

Implementation

IMPLEMENTATION

In recent years, state and other health organizations have significantly enhanced the number and quality of the cancer-related programs conducted in Maine. Most of these, however, came about through issue-specific grants that impose restrictions and limitations on program activities, cross–program collaboration, and planning across cancer sites and risk factors. Although Maine has an existing infrastructure for public-private collaboration in which public health functions are integrated into the larger health system, a formal structure is needed to ensure that comprehensive cancer prevention, control, and care happens in a systematic and synchronized manner.

Maine has successfully completed a comprehensive cancer control planning process with participation from a diverse group of stakeholders. There is a strong commitment from people and organizations in Maine to begin the implementation of this Plan as quickly as possible. The following are objectives and strategies for implementing this Plan.

GOAL 16: Build a comprehensive cancer prevention, control, and care program or coalition that is based on best practices.

Objective 16.1

Establish, support, or become part of, a public/private collaboration that focuses on comprehensive cancer prevention, control, and care (analogous to the Maine Cardiovascular Health Council for cardiovascular disease, see Appendix A for a description of this Council).

Strategies

- Determine what changes, if any, are required in the management/administration of the • Consortium to move forward with implementation of the Plan and to best suit the needs of comprehensive cancer control.
- Seek funding sources to support the collaboration.
- Identify and catalogue cancer prevention, control, and care programs, resources, and best practices in the state of Maine.
- Share programs, resources, and best practices through such means as a newsletter or web site.
- Hold an annual Maine Cancer Prevention, Control, and Care Conference to share best practices, and to identify current and emerging initiatives and activities across Maine.
- Evaluate cancer prevention, control, and care strategies through a review of current literature.
- Inform or make available information about new strategies via listserves and connections with partner websites.
- Initiate listserve management and quality control measures.
- Establish core cancer indicators for communities to gauge their effort and conduct both short- and long-term evaluation.

GOAL 17: Implement the Comprehensive Cancer Control Plan.

Strategies

- Identify priority activities to be implemented first.
- Develop committees or taskforces to work on priority activities.
- Secure funding for priority activities.
- Implement priority activities.
- Evaluate implementation process.
- Identify "next wave" of priority activities to be implemented and begin implementation cycle again after review of new knowledge in the field of cancer prevention and treatment, changes in recommendations and best practices, and cancer and evaluation data.

EVALUATION

EVALUATION

Evaluation has been built into this Comprehensive Cancer Control Plan. Whenever possible measurable objectives have been written and baseline data are provided. These data will be used to measure progress toward objectives.

The focus of the evaluation in the early stages of this implementation process will be to measure progress toward objectives and provide feedback to Consortium members so that motivation and commitment to this Plan remain strong. Data sources exist for many interim objectives such as increases in behaviors shown to reduce cancer risk. Data sources exist for most, if not all, long-term health outcome objectives and will be monitored throughout the implementation phase. Data sources for those objectives that do not have baseline measures will be identified and developed.

GOAL 18: Evaluate implementation of the Maine Comprehensive Cancer Control Plan.

Objective 18.1

Develop an evaluation plan for the Cancer Control Plan by October 2001.

Strategies

- Identify and organize an evaluation work group.
- Determine specific evaluation questions to be answered.
- Determine resources available for evaluation.
- Develop and approve evaluation plan including who will be implementing what strategies and during what time frame.
- Conduct ongoing evaluation.
- Disseminate results annually.
- Review the evaluation plan annually and revise if needed.

Objective 18.2

Develop data sources for those objectives for which baseline data currently do not exist.

Strategies

- Identify gaps in data.
- Determine potential data sources.
- Develop data sources as necessary.

APPENDICES

APPENDIX A
TERMS AND ACRONYMS

ACoS. The American College of Surgeons (ACoS) Commission on Cancer is a scientific and educational association of surgeons that was founded in 1913 to improve the quality of care for the surgical patient by setting high standards for surgical education and practice. It conducts various programs through its Commission on Cancer to improve the care of the cancer patient. It promotes a program that encourages hospitals to develop programs for optimal care of cancer patients and to seek, on a voluntary basis, College approval of these programs.

ACS. The American Cancer Society (ACS) New England Division has been a partner in efforts to reduce the impact of cancer in Maine for many years. The ACS is a community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives from cancer and diminishing suffering from cancer, through research, education, advocacy, and service. ACS has played a key role in developing this Plan and has agreed to provide both monetary and human resources to the support and implementation of this Plan.

Age-adjusted rate. A rate that controls for the age structure of different populations. Age-adjustment allows rates to be compared between population groups with different age distributions. All age-adjusted rates are expressed per 100,000 individuals per year.

ALA. The American Lung Association (ALA) of Maine is a community-based voluntary health organization that has been leading the fight against lung disease since 1911. Through legislation, education, community service, and research, the ALA of Maine's reach extends from the state capitol to every community in Maine. Current efforts of the ALA of Maine include: asthma management, funding to address school indoor air quality problems, and acting as a key partner in the efforts of the newly formed Maine Indoor Air Quality Council, the Smoking OR Health Coalition, and the Partnership for a Tobacco-Free Maine.

BRFSS. The Behavioral Risk Factor Surveillance System (BRFSS) is an ongoing random-digit dialed telephone survey of adults concerning health-related behaviors. The BRFSS was developed by the Centers for Disease Control and Prevention (CDC) and is conducted in all states in the U.S. Each year, approximately 1,200 Mainers are interviewed. The BRFSS includes questions on health behavior such as diet; weight; tobacco and alcohol use; physical exercise; preventive health screenings; and use of preventive and other health care services. The data are weighted to represent all adults aged 18 years and older.

Cancer. A population of abnormal cells showing a growth preference over their normal cellular counterparts.

Cancer incidence. Cancer incidence is the number of newly diagnosed cases of cancer occurring in a population in a given period of time, usually one year. The incidence rate is the number of new cases of the disease expressed as a rate per 100,000 persons in the population.

Cancer mortality rate. Cancer mortality rates reflect the death rate specific to cancer or a particular type of cancer.

CDC. The Centers for Disease Control and Prevention (CDC) is an agency within the United States Department of Health and Human Services.

Children with Special Health Needs Program. A Maine Bureau of Health program that assists children with special health needs such as blood disorders, cardiac defects, childhood oncology, craniofacial anomalies, gastrointestinal disorders, metabolic disorders, ophthalmologic diseases or disorders, orthopedic conditions, neurological conditions, neurosensory conditions, neuromuscular conditions, and respiratory conditions. The mission of Children with Special Health Needs Program is to improve the health and quality of life of infants, children, and adolescents with special health needs.

CHP/CDP. The Community Health Promotion/Chronic Disease Prevention Program assists with organizing and planning interventions to reduce the major risk factors for chronic disease with a special emphasis on community-based approaches.

Colonoscopy. A colorectal cancer screening test consisting of an examination of the upper portion of the rectum with an elongated speculum.

CPACAC. The Cancer Prevention and Control Advisory Committee (CPACAC) was established in 1987 by the state legislature to serve as an advisory body to the Maine Bureau of Health on the operation of the Cancer Registry Program and the development and maintenance of a coordinated statewide approach to cancer prevention and control.

CSHE. Comprehensive School Health Education.

CSHP. Comprehensive School Health Program, statewide, K-12.

HMO. Health Maintenance Organization.

Maine Breast Cancer Coalition. A statewide network of organizations and individuals committed to increasing public awareness of breast cancer; educating women and health care professionals about quality care, including early detection, management, and treatment options; advocating for legislative action; and developing support services for women facing the challenge of breast cancer. The Maine Coalition is a member of the National Breast Cancer Coalition.

Maine Cardiovascular Health Council. The Maine Cardiovascular Health Council is an incorporated nonprofit health agency made up of community health nurses, consumers, physicians, insurers, health educators, administrators, planners, pharmacists, and representatives of labor, industry, and governmental and voluntary agency health education programs. The mission of the Council is to promote cardiovascular health and risk reduction in Maine communities by working cooperatively with other organizations and agencies to improve coordination of resources; and to serve as the Advisory Council to the Bureau of Health's Community Cardiovascular Risk Reduction Program.

Maine Coalition on Smoking OR Health. An independent advocacy group that has been in existence for approximately 20 years. The goal of the coalition is to reduce tobacco use in Maine.
This coalition has broad representation from approximately 150 organizations and people throughout Maine including members from the Medical and Osteopathic Association, the Maine Hospital Association, the American Heart Association, the American Lung Association, the American Cancer Society, and Medical Care Development. With the help of these various members, the Maine Coalition

on Smoking OR Health has been responsible for much of the tobacco legislation that has been passed in the past ten to fifteen years.

Maine Consortium for Office System Improvement. The Maine Consortium for Office System Improvement is a new collaboration aimed at enhancing clinical outcomes, patient satisfaction, and efficiency by working with health care providers to improve office systems.

Mammography. A screening test for breast cancer.

Mastectomy. Surgical removal of the entire breast.

MBCHP. The Maine Breast and Cervical Health Program (MBCHP) is a statewide program that increases financial access to mammograms for low-income women; supports community coalitions to increase outreach and educational efforts; increases provider education regarding breast health; conducts media campaigns to increase awareness of the need for breast cancer screening; among other functions.

MBOH. The Maine Bureau of Health (MBOH) has responsibility for the public health within the Department of Human Services. The mission of the MBOH is to develop and deliver services to preserve, protect, and promote the health and well-being of the citizens of Maine.

MCR. The Maine Cancer Registry (MCR) seeks to reduce the morbidity and mortality due to cancer by providing cancer data for research and intervention programs.

Melanoma. The most serious type of skin cancer.

Metastasizing. A cancer that has spread from the original cancer site to other parts of the body.

Morbidity. A measurement of the extent of disease and disability.

NCI. National Cancer Institute.

NIH. National Institutes of Health.

Oral Health Program. A Maine Bureau of Health program that seeks to improve the oral health of Maine people.

Pap test. A screening test for cervical cancer developed by Dr. Papanicolaou.

PHN. Public Health Nursing (PHN) assists families and communities to prevent and control communicable diseases, help children with special health needs, obtain services from specialty clinics, obtain care for the sick, and support families in stress.

PRAMS. Pregnancy Risk Assessment Monitoring System (PRAMS) is used to monitor health behavior among pregnant women.

PTM. Partnership for a Tobacco-Free Maine (PTM) is a Maine Bureau of Health program. Legislation passed in June 1997 raised the state tobacco product excise tax by 37 cents. Approximately $3.5 million per year from this cigarette tax revenue will be dedicated to PTM in the MBOH. The PTM leads and

administers Maine's tobacco prevention and control program and is responsible for achieving four primary objectives: (1) prevent youth from using tobacco; (2) motivate tobacco users to stop; (3) protect the public from exposure to environmental tobacco smoke and its dangerous health effects; and (4) identify and eliminate disparities in tobacco-related morbidity and mortality among various subpopulations in the state.

PSA. Prostate-specific antigen blood test used to screen for prostate cancer.

SEER. The Surveillance, Epidemiology, and End Results Program (SEER) is a National Cancer Institute network of population-based cancer registries that collects ongoing data on new cancer cases and patient survival rates.

Title X. A program that provides funding for low-income women to receive cervical and other health screenings.

APPENDIX B
MANDATED HEALTH INSURANCE BENEFITS RELATED TO CANCER

Year Enacted	Benefit	Type of Contract Affected
1990, 1997	Benefits must be made available for screening mammography.	All contracts
1995	Must provide coverage for reconstruction of both breasts to produce symmetrical appearance according to patient and physician wishes.	All contracts
1996	Benefits must be provided for screening Pap tests. Effective 1/97.	Group, HMOs
1996	Benefits must be provided for annual gynecological exam without prior approval of primary care physician. Effective 1/97.	Group managed care including HMOs
1997	Benefits provided for breast cancer treatment for a medically appropriate time determined by the physician in consultation with the patient. Effective 1/98.	All contracts including HMOs
1998	Coverage required for prostate cancer screening: Digital rectal examinations and prostate-specific antigen tests covered if recommended by a physician, at least once a year for men 50 years of age or older until age 72. Effective 1/2000.	All contracts including HMOs

Source: State of Maine, Department of Professional and Financial Regulations, Bureau of Insurance, Mandated Benefits, 2000 as reported at url: http://www.state.me.us/pfr/ins/mndtsum.htm

APPENDIX C
SUMMARY OF MAINE TOBACCO LAWS

The legislature has mandated that no smoking is allowed in enclosed places where the public is invited or allowed (restaurants are included in this law as of 9/18/99, some exceptions apply regarding smoke shops, taverns, etc.), in any enclosed area of any hospital, in school buildings, and in areas where employees are doing work.

Smoking in nursing homes is limited to designated areas. In addition, no one can sell, furnish, give away or offer to sell cigarettes or tobacco to any child under the age of 18. Cigarette self-service displays are prohibited except in tobacco specialty stores or where minors are generally prohibited. Cigarette vending machines must be located in areas where minors are not allowed unless accompanied by an adult (American Lung Association of Maine).

APPENDIX D
NATIONAL CANCER PREVENTION AND SCREENING GUIDELINES SOURCES

American Cancer Society
1599 Clifton Road, NE
Atlanta, GA 30333
Telephone: 1-800-ACS-2345
Website: http://www.cancer.org

American Lung Association
1740 Broadway
New York, NY 10019
1-212-315-8700
Website: http://www.lung usa.com

American Gastroenterological Association
7910 Woodmont Avenue, 7th Floor
Bethesda, MD 20814
301-654-2055
Website: http://www.gastro.org

American Association of Dermatology
930 N. Meacham Road
Schaumburg, IL 60173
847-330-0230
888-462-3376
Website: http://www.aad.org

Guide to Clinical Preventive Services, United States Preventive Services Task Force
Website: http://158.72.20.10/pubs/guidecps/default.htm

Agency for Health Care Research and Quality
Website: http://www.ahc.pr.gov/clinic/ppipix.htm

National Comprehensive Cancer Network
50 Huntingdon Pike, Suite 200
Rockledge, PA 19046
Telephone: 888-909-6226
Fax: 215-728-3877
Website: http://www.nccn.org

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